More Than a Shelter: Exploring the Impact of Housing Services among Women with HIV/AIDS in the District of Columbia

A Dissertation

Submitted to the Faculty

of

Drexel University

by

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in partial fulfillment of the

requirements for the degree

of

Doctor of Public Health

December 2016

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Dedications

This dissertation is dedicated in loving memory of Dr. Lisa Ulmer, one of my committee chairs during this long doctoral journey. After relocating to Washington, DC to continue my research with my original committee chair, Dr. Lisa Bowleg, Dr. Ulmer graciously stepped in as the head of my committee, guiding me through this excursion.

From my very first class in the doctoral program, until her passing, Dr. Ulmer was overly generous and selfless with her time and encouragement. Whether it was bringing oatmeal and bananas for us to eat during an early Saturday morning class, arranging for a private tutor when my cohort was failing biostatistics, or just being considerate and understanding as I struggled to prioritize my research in the midst of relocating and working full-time, her thoughtfulness was supreme. Dr. Ulmer's dedication to her students and the School of Public Health is unmatched. I was honored to have her serve as my advisor and deeply regret not finishing this journey before her passing. She has forever changed my life and I pray that she is proud.

Acknowledgements

My doctoral pursuit was a long difficult process where I trekked across states, faced loss, and numerous obstacles. There were so many encouraging people along the way that helped make this dream project possible.

The Women's Collective, Inc. welcomed me with open arms, providing space and a wonderful group of women to begin this photovoice project with. Particular thanks goes to Founder/Executive Director, Patricia Nalls; Community Health Worker, Sabrina Heard; and Tifphane Riley, Director of Care Programs for being my gatekeepers at The Collective. More so I feel blessed to have bonded with the women who participated in the More than a Shelter project (MTS). Their passion and commitment to MTS was beyond what I anticipated.

When I was unable to secure a grant for MTS, my family, friends, teammates and coworkers volunteered time and resources that were instrumental to the project. While the MTS ladies and I sent thank you cards to those that financially donated to the project, there were other behind-the-scenes contributors that deserve recognition. Dr. Michelle Teti, thank you for introducing me to photovoice, and allowing me to work on "Sharing Stories," the project that sparked the inspiration for MTS. Kenyon Alston for reminding me that I am not super woman, and that even help running errands and stuffing folders goes a long way. Chef Quiana Ford for not only catering our group

meetings, but also bringing me snacks and supporting me during the writing process. Also, Jessica Mandell, Emma Gaquin and Michael Barney for helping with transcription. Kátrina Clowers Taylor, my long-term friend, thank you for serving as the professional photographer, providing technical assistance with cameras, training, graphic design and vision for the future displays of the project. Special thanks to my colleague Sidney Holt for helping me work through theoretical hang-ups during my analysis.

Jennifer Bowles, the other half to my 2-person cohort, I absolutely could not have completed this program without you. You were the best "school wife" possible and I cherish all the laughs, tears, griping and soul searching conversations about social justice. You have remained my battle buddy—even after I left for DC—in the struggle to pursue this degree by doing research that we truly believed was meaningful.

My dissertation committee, Dr. Suruchi Sood and Dr. Renee Turchi, I greatly appreciated you sharing your knowledge of photovoice and women's health, but also your patience during the formative stages of this long project. Christine Campbell, I am forever grateful that you accepted my committee invitation and took a chance on a student that stalked you at a HIV/AIDS Housing conference in Montreal. When I proposed this project I knew very little about HIV/AIDS housing efforts; your community and policy expertise was invaluable. Dr. Augusta "Toti" Villanueva, thank you for stepping up as my

third committee chair during this journey. When Dr. Ulmer passed you immediately took me under your wing. Your continued reassurance helped me stay motivated to see this thing through. My mentor, boss, and friend, Dr. Lisa Bowleg, you have challenged, carried and encouraged me to a higher level of critical and theoretical thinking, and dared me to strategically confront my writing fears. Yet, more importantly, you've really inspired me to a higher level of self-reflection and consciousness as a professional Black woman. There are not enough thanks in the world for the role you've played in my research and life.

Lastly, I must highlight my incredible support system. My friends, Ashley, Keri, Denna and Taylor, for always having faith in the project, and me, even when I doubted myself. My older brother, Kamau and particularly my older brother and sister Kellen and Leatrice, thank you for your relentless support and encouragement for everything I set to achieve. My father, Robert, raised me to be aggressive in my academic pursuits and mindful of the world around me. I always strive to make you proud. Just know your reminders to "put the football down and get to writing" were needed. Finally my mother, Yvonne, you have shown more patience than anyone during this trip. I could not have made it to this point without your prayers, love and willingness to sit through my teary phone calls. I only wish the rest of my tribe of strong women—Grandmom Barbara and Doretha, Nan and Aunt Rhoda—were here to witness.

"What we do for ourselves dies with us. What we do for others and the world remains and is immortal."

--Albert Pike

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List of Abbreviations/Acronyms

CBPR	Community-based participatory research
CRA	Community Research Assistants
DOH	Department of Health
GWU	George Washington University
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
HOPWA	Housing Opportunities for Persons with AIDS Program
HUD	US Department of Housing and Urban Development
IP	Interpretive Phenomenology
MTS	More than a Shelter Project
PI	Principal Investigator
PLWHA	People living with HIV/AIDS
SEM	Social Ecological Model
TWC	The Women's Collective
UHF	Urban Health Framework
WHO	World Health Organization
WLHA	Women living with HIV/AIDS

Abstract

More Than a Shelter: Exploring the Impact of Housing Services among Women with HIV/AIDS in the District of Columbia
Jenné Shayleen Massie

Background. The Housing Opportunities for Persons with AIDS (HOPWA) Program is a national structural approach designed to address housing instability including providing linkages to health care and mental health services for people living with HIV/AIDS (PLWHA) and their families. While there is literature supporting the association between HOPWA and positive health outcomes, there is a dearth of research examining its broader impact on women living in HOPWA-funded housing. This study focused on the experiences of a cluster of PLWHA living in Washington, DC in need of housing, including the use of photovoice methods, to explore, analyze, and document the impact of HIV/AIDS-sponsored housing services on their lives.

Methods. The study's participants (N = 9) and researcher relied on both individual and group photo discussions to create critical discourse, observations, reflections, discussion, feedback, and interpretations of the data collected to gain a culturally-grounded and contextual understanding of the impact that HOPWA-funded housing plays on the lives of WLHA in Washington, DC. The study further used a structured sequential step methodology that included a three-phase process for conducting a photovoice project to engage a cluster of women living in HOPWA-

funded housing. Phase 1 of the study included gathering experiential data by conducting personal interviews with the women about their experiences, including their reflections about photos they took, using photovoice methods to accurately identify and describe in detail the essential themes emerging from their personal accounts. Phase 2 of the study involved presentation and group discussion of the experiential themes identified and detailed by the participants. Finally, Phase 3 involved the interpretative phenomenological using the Urban Health Framework and intersectional analyses of this study's research process, including qualitative data collected as part of the above noted Phases 1 and 2.

Results. A majority of the women were unfamiliar with the HOPWA program, having acquired stable housing through other HUD programs including, for example, the Housing Choice Voucher Program. Participants perceived access to housing services in DC to be limited in scope, and the process of securing and maintaining stable housing was described as being extremely difficult. The women experienced long waiting times – sometimes extending decades -- while seeking to secure housing, and perceived their gender, race, and class as being major barriers to qualifying for some housing opportunities. Some participants noted that their access to housing had a positive impact on their health promoting behaviors and facilitated social support with family and friends by meeting their basic need for shelter and reducing stress. However, the women's experiences with subsidized housing often exposed them to mold, pests, dilapidated structures, violence, and economic and racial segregation

caused, in part, by rapid gentrification. The physical and complex social environments faced by these women had a significantly negative effect on both their physical and mental health. Participants asserted that women's HIV/AIDS and housing needs were not being met in DC, and that policymakers were not addressing their priorities as WLHA. Participation in the study had a direct benefit for participants that gained self-empowerment and were able to advocate for improvements in accessing adequate housing through participatory action.

Conclusions. Women accessing HIV/AIDS housing-sponsored services in DC were often subjected to sub-standard living conditions, with little power or resources to improve their living conditions. Participation in this study's photovoice project led to engagement in critical dialogue, self-empowerment, and action that resulted in the improvement of some participants' living conditions, as well as advancing advocacy in support of women's HIV/AIDS housing services needs in DC.

CHAPTER I: INTRODUCTION

1.1 Background of the Problem

Early HIV/AIDS prevention efforts mainly focused on individual risk behaviors among people disproportionately affected, particularly gay men and injection drug users. Since then, the focus of public health efforts has broadened to include other disproportionately affected groups including heterosexual women and youth. HIV/AIDS prevention and intervention efforts employ a public health approach, that include direct and indirect behavioral interventions ("Community-level HIV intervention in 5 cities: final outcome data from the CDC AIDS Community Demonstration Projects," 1999; Diallo et al., 2010; DiClemente & Wingood, 1995; Ehrhardt et al., 2002; Kalichman et al., 2001; Kamb et al., 1998; Kelly et al., 1991; Lauby, Smith, Stark, Person, & Adams, 2000; Wingood et al., 2004). The public health field now also takes social and structural conditions (i.e. poverty, homelessness, policy, etc.) into consideration, and encourages the integration of effective prevention activities and treatment interventions (Holtgrave et al., 2007; Kidder, Wolitski, Royal, et al., 2007). HIV/AIDS housing and support services have proven to be both an effective prevention and intervention strategy (Holtgrave et al., 2007; The White House Office of National AIDS Policy, 2010).

1.2 Statement of the Problem

Women living with HIV/AIDS (WLHA) who are unstably housed face overlapping syndemics related to physical and mental health, drug use, violence, trauma and early death (Kidder, Wolitski, Campsmith, & Nakamura, 2007). They often face a complex web of social and structural conditions (e.g., poverty, unemployment, racial discrimination) that adversely influence their lives (Riley, Gandhi, Hare, Cohen, & Hwang, 2007). As a result of the vulnerabilities that unstably housed WLHA experience, housing has become a primary focus in many national HIV/AIDS prevention and intervention efforts (The White House Office of National AIDS Policy, 2010). The Housing Opportunities for Persons with AIDS (HOPWA) Program is an example of these efforts (Office of Community Planning and Development, 2012). HOPWA uses a structural approach to address housing instability and linkage to health care and mental health services for people living with HIV/AIDS (PLWHA) by providing housing subsidy assistance, housing development, supportive services (e.g., case management, behavioral health , meals and nutrition, transportation, employment services, and benefits assistance) and housing placement assistance (Office of Community Planning and Development, 2012). While quantitative research findings support the correlation between HOPWA and positive health outcomes (e.g. improved mental health, self-perceived physical functioning, and

viral load) (Scott, Ellen, Clum, & Leonard, 2007; Wolitski et al., 2010), there is limited research that examines the broader impact of the HOPWA program, particularly from the perspective of women living in and receiving HOPWA-funded housing assistance; specifically, what are the effects of what is often substandard housing on their health (e.g. providing stability for WLHA to make decisions related to health promotion) (Cederbaum, Wenzel, Gilbert, & Chereji, 2013; Scott et al., 2007).

1.3 Purpose of the Study

For my dissertation I used photovoice methods; a community-based participatory research (CBPR) strategy that involves having women take photographs to document the reality of their lives, in combination with phenomenological inquiry to explore the impact of housing on the lives of women living in HOPWA-funded housing in Washington, DC. The study places a priority on using photovoice data to conduct phenomenological analysis of the experiences of women living WLHA. The aim of the study was to understand the potential breadth of the impact that HOPWA housing has on WLHA's lives, and to qualitatively identify potential mechanisms of change that lead to the positive health outcomes associated with the HOPWA program (Scott et al., 2007; Wolitski et al., 2010).

1.4 Specific Aims

Many women in poor urban areas are experiencing housing instability and homelessness (ACT Up Philadelphia, 2010; Cederbaum et al., 2013; Clampet-Lundquist, 2003; Magnus et al., 2014; National Coalition for the Homeless, 2009), which leads to a complex web of social and structural factors that shape their lived experience (i.e., poverty, unmet subsistence needs, constrained survival choices, substance abuse, risky sexual behavior) (Forney, Lombardo, & Toro, 2007; Riley et al., 2007). This study aims to use photovoice techniques to explore the impact of HOPWA-funded housing program on the lives of WLHA in Washington, DC. The proposed study has three specific aims:

1. To describe the experiences of WLHA utilizing HOPWA-funded services in Washington, DC.

2. To identify mechanisms and barriers associated with HOPWA housing and WLHA's health behaviors and positive health outcomes (i.e. improved medication adherence, reduced emergency room visits and hospitalizations, reduced self-reported opportunistic infections and improved mental health status).

3. To understand if the HOPWA program is meeting the needs of WLHA in Washington, DC.

1.5 Importance of the Study

My dissertation addresses a critical public health need by trying to understand the relationship between HOPWA housing and the positive health

outcomes (e.g. improved self-reported physical and mental health) often reported in quantitative AIDS housing research (Department of Housing and Urban Development, 2017; HUD, 2012; Wolitski et al., 2010). Phenomenological inquiry has the potential to capture experience in process as lived, through descriptive analysis and has been used successfully in health research with WLHA (Benner, 1994; Rose, Pugh, Lears, & Gordon, 1998). The study is innovative in that it is multi-method approach incorporates photovoice with phenomenological inquiry to garner information (Plunkett, Leipert, & Ray, 2013) about the complex web of social and structural factors that influence the experiences of WLHA living in HOPWA-funded housing (Cederbaum et al., 2013; Kidder, Wolitski, Royal, et al., 2007). This unique project directly aligns with local (The Department of Housing and Community Development, 2011) and national agendas (ONAP, 2010; The White House Office of National AIDS Policy, 2010) to address the HIV/AIDS health disparities particularly within populations such as racial/ethnic minority women and women experiencing poverty in housing instability, while also aiding in the District's initiative to assess the housing needs for PLWHA (HAHSTA, 2012).

1.6 Scope of the Study

The District of Columbia's Department of Health's most recent needs assessment identified a service gap in affordable housing for PLWHA

(HAHSTA, 2012). The results from this study provide a qualitative supplement to the City's housing assessment needs of WLHA. Consistent with CBPR principles (e.g., working with community members to implement research and disseminate findings) (Barbara A Israel et al., 2008), I plan to share the results with community-based organizations providing residential support services to PLWHA in DC, HOPWA-funded programs, the District's Department of Health HIV Prevention Planning Group, HIV/AIDS housing advocacy organizations and other HIV/AIDS housing researchers.

1.7 Definition of Terms

Housing Instability: Visible forms of homelessness (i.e., sleeping on the street or shelter), less visible forms (i.e., couch surfing and exchanging sex for shelter), and marginal housing (i.e., single room occupancy or hotel) (Riley et al., 2007).

Photovoice: Participatory action research method that combines photography with social action, typically used with people from marginalized populations (C. Wang & Burris, 1997; C. C. Wang, 1999).

Phenomenology: The study of experience or subjective experience. Social, cultural and personal meaning are a part of the experience (Merleau-Ponty, 1996; Plunkett et al., 2013).

Interpretive Phenomenology: Qualitative research approach that looks at phenomenon within the context of the lived experience (Benner, 1994). Reflection and interpretation are used in interpretive phenomenology to understand the experience and its meanings (Lopez & Willis, 2004). Participants are considered co-researchers in the inquiry process and the method finds value in the subjective experience. For this reason, participants will be referred to as Community Research Assistants.

Essence: Essential or common themes that explain a phenomenon and its meaning (Chamberlain, 2009). Essence is understood through the process of interpretation and reflection of the experience by the participant (Merleau-Ponty, 1996) .

Bracketing: An attempt to acknowledge and explain the researcher's preconceptions, assumptions, and biases in phenomenological inquiry (Chamberlain, 2009). The rigor of the study often rests on the researcher's ability to acknowledge and explain their thoughts, responses and decisions during the course of the research process (Donalek, 2004).

CHAPTER II:REVIEW OF THE LITERATURE

2.1 History and Definition of the Problem

The World Health Organization (WHO) defines social determinants of health as the circumstance in which people live and the social, economic and political forces that shape these experiences (World Health Organization, 2010). Within public health, gaining understanding of the social determinants of health is a key step in developing effective prevention and intervention programs (Smedley & Syme, 2001; Solar & Irwin, 2007; Wilkinson & Marmot, 2003). Part of this exploration, particularly for behavioral scientists, includes gaining understanding of the context of people's lives and the social-structural factors that impact everyday life and living conditions (Shaw, 2004; Sumartojo, 2000). Within the WHO crusade to make social determinants of health a key part of public health research and programs, the organization has identified housing and living conditions as key social determinants of health due to considerable effect housing and living conditions have on people's health and well-being (i.e., risky behaviors, substance use, mental health, respiratory health, acute and chronic illness) (CSDH, 2008; Krieger & Higgins, 2002; Shaw, 2004). The WHO went even further by recognizing access to affordable housing as a fundamental human right (CSDH, 2008).

With housing having such a priority in global (CSDH, 2008) and national public health agendas (The White House Office of National AIDS Policy, 2010; USDHHS), it has also appeared as a common topic in recent public health research (Davey-Rothwell, Latimore, Hulbert, & Latkin, 2011; Fitzpatrick-Lewis et al., 2011; Henwood et al., 2013; Jones-Rounds, Evans, & Braubach, 2014; Ruel, Oakley, Wilson, & Maddox, 2010). Empirical research has found an association between housing status, particularly housing instability and homelessness and increased HIV risk behaviors amongst PLWHA (Adimora & Auerbach, 2010; A. A. Aidala & Sumartojo, 2007; A.A. Aidala, Lee, Abramson, Messeri, & Siegler, 2007; Cisneros, 2007; Kidder, Wolitski, Royal, et al., 2007; Leaver, Bargh, Dunn, & Hwang, 2007; Riley et al., 2007; Riley et al., 2012; Shubert & Bernstine, 2007; Wolitski, Kidder, & Fenton, 2007; Wolitski et al., 2010). These risk behaviors include substance use and abuse, having multiple sexual partners, exchange sex, and unprotected sex (A.A. Aidala et al., 2007; Elifson, Sterk, & Theall, 2007; Kidder, Wolitski, Royal, et al., 2007; Knowlton et al., 2010; Leaver et al., 2007; Riley et al., 2007; Riley et al., 2012; Wolitski et al., 2007; Wolitski et al., 2010). While researchers have theorized that factors such as improved self-esteem, social support and depressive systems may be a potential link between housing and decreased HIV risk behaviors, a clear mechanism has yet to be identified (A. A. Aidala & Sumartojo, 2007). With HIV/AIDS plaguing vulnerable communities

within the United States such as people that are homeless and those experiencing housing instability, researchers are still trying to uncover the nature and direction of the relationship between housing status and HIV/AIDS and related risk behaviors (A. A. Aidala & Sumartojo, 2007).

2.2 Extent and Consequences of the Problem

Epidemiological research on housing status has shown an intersection between homelessness or housing instability within the United States and HIV/AIDS (Culhane, Gollub, Kuhn, & Shpaner, 2001). A large-scale study within Philadelphia found that the homeless population that utilized homeless shelter services within the city were nine times more likely to have AIDS than the general population and that people with AIDS were three times more likely to use homeless shelters than the general population (Culhane et al., 2001). This epidemiological data has been used to support housing as a major focus in HIV/AIDS prevention efforts (A. A. Aidala & Sumartojo, 2007; Cisneros, 2007; ONAP, 2010; Shubert & Bernstine, 2007; Wolitski et al., 2007).

In addition to exploring the role that housing status plays in HIV risk behaviors and transmission, there is empirical evidence that shows a relationship between housing status and the health outcomes of previously diagnosed PLWHA. Housing status is a key determinant of HIV survivorship and utilization and adherence to HIV medical care and antiretroviral therapy (ART),

particularly amongst homeless racial/ethnic minority populations (A.A. Aidala et al., 2007; Jannette Berkley-Patton, Kathleen Goggin, Robin Liston, Andrea Bradley-Ewing, & Sally Neville, 2009). Research has documented that death rates for homeless PLWHA are as much as five times higher than the death rates of the general PLWHA population (Cisneros, 2007).

The White House suggests that the increased medical cost to treat HIV/AIDS and the poverty faced by many vulnerable communities plagued by the disease only compounds the critical circumstances surrounding housing and HIV/AIDS (i.e., co-occurring health conditions, employment, access to physical and mental health care services, challenges meeting basic needs), and makes the loss of housing due to economic conditions another concern for PLWHA (ONAP, 2010; The White House Office of National AIDS Policy, 2010). These barriers to acquiring and maintaining affordable housing make adherence to HIV/AIDS medical treatment that much more difficult, which can consequently lead to poorer health outcomes (Cisneros, 2007; ONAP, 2010).

Similar to what has been conceptualized in Maslow's (1999) Hierarchy of Needs, qualitative research findings regarding HIV-positive racial/ethnic minorities (J. Berkley-Patton, K. Goggin, R. Liston, A. Bradley-Ewing, & S. Neville, 2009) and HIV housing policy research with PLWHA (Cisneros, 2007; Leaver et al., 2007) suggest that meeting basic needs such as food and shelter

often trump seeking health care as a daily priority, particularly for PLWHA experiencing homelessness or housing instability (J. Berkley-Patton et al., 2009; Cisneros, 2007; Leaver et al., 2007; Maslow, 1999). In addition to food and hygiene, housing has proven to be a key predictor of poor physical health for among HIV-positive men (Riley et al., 2012). Henry Cisneros, the former Secretary of the US Department of Housing and Urban Development (HUD) has gone as far to say that housing stability may be the key factor in determining the length and quality of life for PLWHA (Cisneros, 2007). Empirical findings support a demand for more structural interventions that address the housing needs of PLWHA and research that examines how these interventions affect the lives of WLHA.

2. 3 Key Determinants of the Problem

Women are an increasingly growing subgroup within the U.S. population experiencing housing instability and the homeless community (Arangua, Andersen, & Gelberg, 2005; CSDH, 2008; Elliott, Golinelli, Hambarsoomian, Perlman, & Wenzel, 2006). Racial/Ethnic minority women are disproportionately represented among people experiencing homelessness and housing instability and face unique health and health care disparities, which include high HIV/AIDS incidence and prevalence rates (Gelberg, Browner, Lejano, & Arangua, 2004; Teruya et al., 2010).

As previously stated, homelessness and housing instability have been correlated with increased HIV risk behaviors (A. Aidala, Cross, Stall, Harre, & Sumartojo, 2005); for homeless women this often translates to high rates of sex with multiple partners, sexual intercourse without contraception, and exchange sex for money or drugs (Adams, 2003; Forney et al., 2007; Riley et al., 2007). Homeless women also encounter additional hardships related to health and accessing healthcare due to sexual and reproductive needs not experienced by homeless men including birth control, family planning, women's health services, intimate partner violence and childcare (Gelberg et al., 2004; L. A. Smith & Pynoos, 2002). Research with women that were homeless or unstably housed described women as having constrained survival choices, and that understanding the effects social and structural contexts on risk behavior is an important step in public health efforts to meet the needs of homeless WLHA (Riley et al., 2007; Riley et al., 2011; Sohler, Li, & Cunningham, 2007).

A complex web of physical and sexual abuse, substance use, partner violence, psychiatric disorders, incarceration and poverty often characterizes the lives of women who are homeless (Caton et al., 2012; Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009). The combined burdens of housing instability, adverse physical health and often compounding mental health concerns (Schanzer, Dominquez, Shrout, & Caton, 2007) make prevention efforts

for homeless and unstably housed WLHA that much more pertinent (Dickson-Gomez, McAuliffe, Convey, Weeks, & Owczarzak, 2011). In order to give a visual display of the complex web of social and structural factors that shape the context of the lived experience for women that are homeless or experiencing housing instability, I have included a diagram of the social ecological model (McLeroy, Bibeau, Steckler, & Glanz, 1988) in Figure 1, which served as a conceptual framework during the initial development of my dissertation. Subsequently, I adapted the Urban Health Framework (UHF)(Galea & Vlahov, 2005) and Intersectionality Framework as a theoretical lenses during analysis, which are discussed in detail in Chapter III.

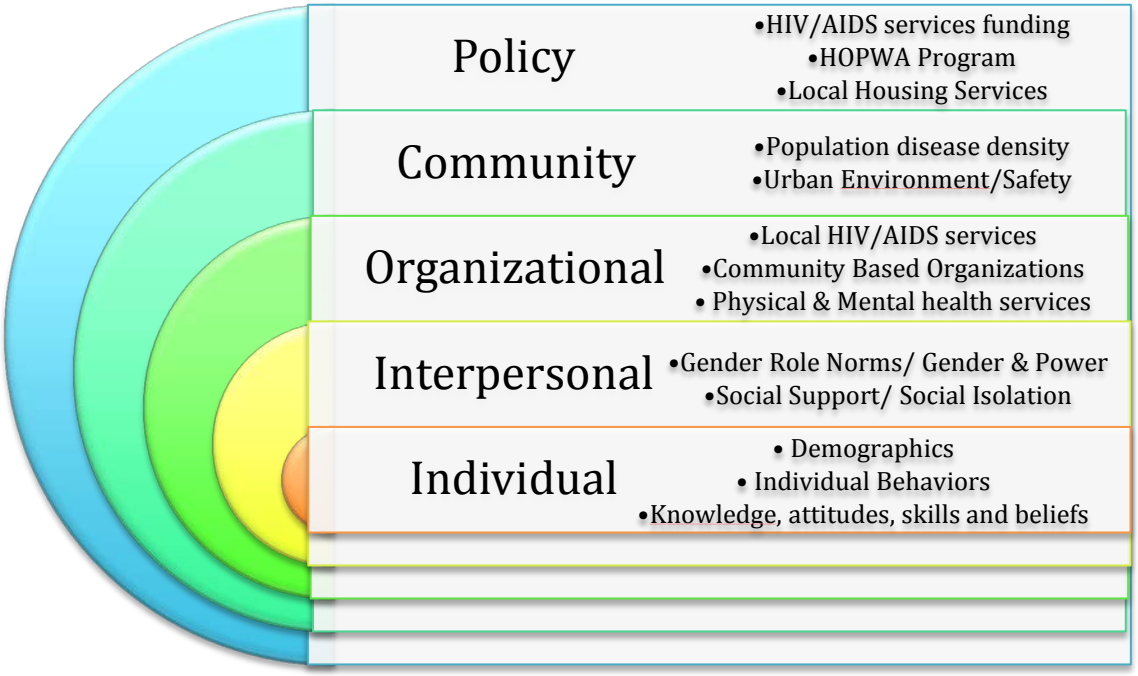


Figure 1: A Social Ecologic Model (McLeroy et al., 1988): WLHA Experiencing Homelessness/Housing Instability

HIV/AIDS housing research has largely focused on housing as an HIV prevention and intervention strategy (Adimora & Auerbach, 2010; Holtgrave et al., 2007), (Dickson-Gomez et al., 2011; Holtgrave et al., 2012). Research has also examined the relationship between housing status and health related outcomes (i.e., access to care, continued care, medication adherence, substance use, sexual risk behaviors, etc.)(A. Aidala et al., 2005; Cederbaum et al., 2013; Coady et al., 2007; Dickson-Gomez et al., 2011; Douaihy, Stowell, Bui, Daley, & Salloum, 2005; Kidder, Wolitski, Campsmith, et al., 2007). The bulk of this research is

quantitatively driven, including limited coverage regarding how improved housing stability or housing intervention programs are associated with positive health-related outcomes (A. A. Aidala & Sumartojo, 2007). Researchers theorize that improved mental health (e.g., self-esteem, decreased depression, improved social support) (A. A. Aidala & Sumartojo, 2007) and the meeting of basic needs (Maslow, 1999) may explain this association. However, these hypotheses do not consider the complex intersections of race, gender, and class in relation to housing status and HIV/AIDS (Adimora & Schoenbach, 2005; Cederbaum et al., 2013), particularly for WLHA experiencing housing instability (C. Rollins et al., 2012; J. H. Rollins, Saris, & Johnston-Robledo, 2001). WLHA experiencing housing instability are disproportionately represented by impoverished minority women (Project Home, 2013), so it is vital that this study consider inequalities based on the intersecting identities related to race, gender and class within the context of these women's lives and experiences (Adimora & Schoenbach, 2005; Bowleg, 2012; Clampet-Lundquist, 2003; Sanders & Ellen, 2010). I have chosen to use intersectionality-informed qualitative research in order to explore the complexity and richness of the different life experiences of WLHA receiving HOPWA services, and how their experiences relate to power, privilege and policy associated with housing (Bowleg, 2012; Collins, 1993; Hunting, 2014).

2.4 Intervention Strategies

In response to the need for a more structural approach to address the HIV/AIDS epidemic among people that are homeless and unstably housed (Adimora & Auerbach, 2010; The White House Office of National AIDS Policy, 2010), housing programs such as the Housing Opportunities for Persons Living with AIDS Program (HOPWA)(Office of Community Planning and Development, 2012) have become one of the largest federally funded HIV/AIDS prevention and intervention efforts nationally (The National AIDS Housing Coalition, 2012) and locally in DC (AIDS Activities Coordinating Office, 2012; HAHSTA, 2012; Office of Housing and Community Development, 2014; The Department of Housing and Community Development, 2011). HOPWA was founded in 1992, regionally operated by the DC Department of Health, HIV/AIDS, Hepatitis/STD/TB Administration (HAHSTA), and funded by the U.S. Department of Housing and Urban Development and Primary Prevention Grants (The Department of Housing and Community Development, 2011; Wolitski et al., 2010). Nationally, housing assistance activities including tenant-based rental assistance, permanent housing facilities, transitional/short-term housing and short-term rent, mortgage and utility assistance, make up almost 60% of the Program's expenditures (The National AIDS Housing Coalition, 2012). Supportive services (e.g. nutritional services, mental health, drug and

alcohol treatment; and assistance in gaining access to local, state, and federal government benefits) account for more than 26% of expenditures and administration and management services (7.4%) , housing placement assistance (4.4%) and housing development (2.2%) account for the remaining HOPWA expenditures (The National AIDS Housing Coalition, 2012). HOPWA housing subsidy beneficiaries reflect the disparate impact of HIV on racial/ethnic minority women with more than 84% of HOPWA-eligible individuals identifying as Black or African American, and 45% as cisgender women (Office of Community Planning and Development, 2012), with 53% identifying as male and 2% transgender.

In the 1980's and 1990's HIV/AIDS prevention and intervention strategies focused almost exclusively on individual risk behaviors, testing, and treatment particularly for populations considered to be at risk such as men that have sex with men (Centers for Disease Control and Prevention, 1987; Martin, 1987), pregnant or breast feeding women (Centers for Disease Control and Prevention, 2006), and injecting drug users (Des Jarlais et al., 2005). Some key primary and secondary prevention strategies at the time included educating populations about and increasing access to HIV testing, counseling and condom use, social marketing and abstinence-only programs (Adam et al., 2009; Bingenheimer & Geronimus, 2009; Merson, O'Malley, Serwadda, & Apisuk, 2008).

In the late 1990's and 2000's primary and secondary prevention and intervention efforts expanded to include social and behavioral interventions on an individual, group and community level to reduce HIV-risk behaviors (Bingenheimer & Geronimus, 2009; Centers for Disease Control and Prevention, 2012), structural interventions (e.g., changes in laws and policies related to syringe exchange and integration of HIV , STD, Viral Hepatitis and TB service organizations) (Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008), and biomedical interventions (e.g. ART and Pre-Exposure Prophylaxis) (Rotheram-Borus, Swendeman, & Chovnick, 2009). There has also been a shift by the CDC towards "prevention with positives" (people living with HIV/AIDS) (Fisher & Smith, 2009; Gerbert et al., 2006; Marhefka et al., 2013). The CDC's Diffusion of Effective Behavioral Interventions project (DEBI) began in 1999 and features effective HIV/AIDS interventions that have undergone rigorous evaluation, often using randomized-controlled trial research methods (Centers for Disease Control and Prevention, 2013). Currently, the project highlights eight biomedical, and 74 behavioral interventions (Centers for Disease Control and Prevention, 2013) as well as some social marketing, structural interventions and public health strategies (Danya International, 2013). Housing was not a key focus in these interventions.

Most recently, HIV/AIDS prevention and intervention research has encouraged the integration of effective structural interventions with prevention activities and treatment efforts. The National HIV/AIDS Strategy (NHAS) has noted the integration of STI/HIV care and prevention as a critical component for reducing the HIV epidemic in the U.S. (ONAP, 2010). In order to reach the NHAS goals of reducing new HIV infections, increasing access to care, improving health outcomes for PLWHA and reducing HIV-related health disparities, researchers and service providers need to combine behavioral, biomedical and public health approaches (Centers for Disease Control and Prevention, 2012; ONAP, 2010) in order to address the complex social-structural factors driving the epidemic.

2.5 Critical Issues

Prior research on housing and the HIV/AIDS community has faced many methodological challenges in terms of how housing status is defined (A. Aidala et al., 2005; Dickson-Gomez et al., 2011) and understanding causal relationship between housing and health outcomes (Dickson-Gomez et al., 2011) . Researchers have found it challenging to evaluate structural interventions such as HIV/AIDS housing because of the lack of clear definitions of housing, methodological challenges, and the complex intersection of social, economic,

political and environmental factors (Gupta et al., 2008) related to HIV risk and behaviors.

U.S. HIV/AIDS research on housing as prevention or intervention have largely focused on men that are homeless (Kidder, Wolitski, Royal, et al., 2007) or substance users. These studies tend to focus on quantitative measurements of health outcomes associated with housing such as access and utilization of healthcare, treatment adherence, and HIV/AIDS health measures including CD4 counts and viral loads (Kidder, Wolitski, Royal, et al., 2007; Leaver et al., 2007). However, few if any studies have examined the factors associated with these improved health outcomes or utilized qualitative methods to explore how those living with HIV/AIDS view their experience with housing programs and services like HOPWA (Furlotte, Schwartz, Koornstra, & Naster, 2012). The National AIDS Housing Coalition maintains a database of HIV/AIDS housing peer-reviewed articles (The National AIDS Housing Coalition, 2014). Out of a total of 454 articles in the database, only 17 focus on cisgender women in the U.S., four of which used qualitative methods (Cederbaum et al., 2013; Mahadevan & Fisher, 2010; Ryan et al., 2009; Scott et al., 2007). Only one study focused on how housing interventions such as HOPWA affected WLHA's experiences (Scott et al., 2007). The study highlighted that city-to-city variability in housing assistance programs for PLWHA affected women's experiences with housing and HIV care (e.g.

different housing opportunities based on city's funding for housing assistance programs), and advocated for HIV/AIDS housing research focused on the local context of housing programs and its effects on the lives of WLHA (Scott et al., 2007). For example, while cities such as Washington, DC and Chicago use a decentralized model of funding housing assistance, pooling together funds from different resources including but not limited to HOPWA to address homelessness as a whole, where PLHA are a key population (HAHSTA, 2012; Scott et al., 2007), heavily funded cities such as New York City use HOPWA funds to provide permanent housing assistance to PLHA (Scott et al., 2007).

WLHA face unique barriers and needs related to their HIV care and health (Caton et al., 2012; Elifson et al., 2007; Gagnon & Holmes, 2012; Riley et al., 2007; Scott et al., 2007; Wolitski et al., 2009). Further research needs to be conducted to understand the ramifications of HIV/AIDS housing programs on the daily lives of WLHA (Greene et al., 2010; Scott et al., 2007), particularly for HOPWA, the largest funded HIV/AIDS housing program in the U.S. (The National AIDS Housing Coalition, 2012).

CHAPTER III: METHODS

3.1 Context of Study

Despite HOPWA exceeding annual performance goals for providing housing and related support services to PLWHA (HUD, 2012), and the Program's proven capacity to improve the housing status and health outcomes of PLWHA, (Wolitski et al., 2010), HOPWA continually faces budget cuts and controversial funding barriers (National AIDS Housing Coalition, 2016). It is critical that research begins to explore how the HOPWA program leads to positive health outcomes for PLWHA to continue to advocate for appropriate funding (National AIDS Housing Coalition, 2016; Wolitski et al., 2010). Part of assessing the efficacy of programs such as HOPWA should also entail gaining a clear understanding of how these programs serve the diverse needs of different subpopulations (i.e. housing service needs of WLHA may differ from housing service needs of men that have sex with men), and the mechanisms within the program that lead to improved housing status and health outcomes (HUD, 2012; Wolitski et al., 2010). HIV/AIDS housing research findings must go beyond basic associations between housing status and viral load counts, to attain a deeper understanding of how HOPWA housing positively or negatively affects the lives of WLHA experiencing housing instability.

3.2 Study Design

This study utilized an interpretive phenomenological inquiry approach in conjunction with Photovoice methodology (Plunkett et al., 2013). Interpretive phenomenology (IP) theorizes that individuals' experiences are influenced by the world they live in (Heidegger, 1962) and their subjective experiences are linked to the social, cultural and political contexts in their world (Leonard, 1989). The study engaged WLHA utilizing HOPWA services in DC in IP, a cyclical process of observation, reflections, discussion and feedback and interpretation on the participants' experiences and daily life (Flood, 2010). Participants, known as Community Research Assistants (CRA), used the information gathered from photos and discussion sections to frame their experiences associated with HOPWA-funded housing and services and health outcomes. This multi-method approach (Plunkett et al., 2013) is intended to lead to a richer understanding of the role that housing plays in health outcomes and the context of daily life for WLHA in urban areas such as the District. Pursuant to CBPR principles (e.g., collaborative community partnerships in all phases of research, cyclical and iterative process, dissemination of findings to community partners) (Barbara A Israel et al., 2008), I collaborated with local HOPWA housing program staff and CRAs to ensure the project was respectful and responsive to the needs of the

women, in order to enhance the understanding of the impact of housing programs on the lives of WLHA in DC.

Phenomenology is a rather complex qualitative methodology (Gelling, 2010, 2011) and can be conducted using a structured sequence of steps or through a more fluid or flexible process that is discovery-oriented that follows the direction of the experience (Flood, 2010). As a novice researcher new to the phenomenological process, I elected to use a structured sequential step phenomenological inquiry rather than a fluid discovery-oriented approach (Flood, 2010) to provide structure and guidance to ensure that this study was methodologically sound. The structured steps included a three-phase process for conducting phenomenological inquiry (Flood, 2010; Seidman, 2012) of women living in HOPWA housing (see Figure 2) described in further detail in section 3.2.2.. For data collection, the study weaved the Plunkett, et. al. (2013) photovoice data collection process as part of the above-mentioned three-phase phenomenological inquiry process (See Figure 4) described in further detail in section 3.2.1.. Photovoice has also been effectively used as a research method with people from marginalized communities such as WLHA (C. C. Wang, 1999).

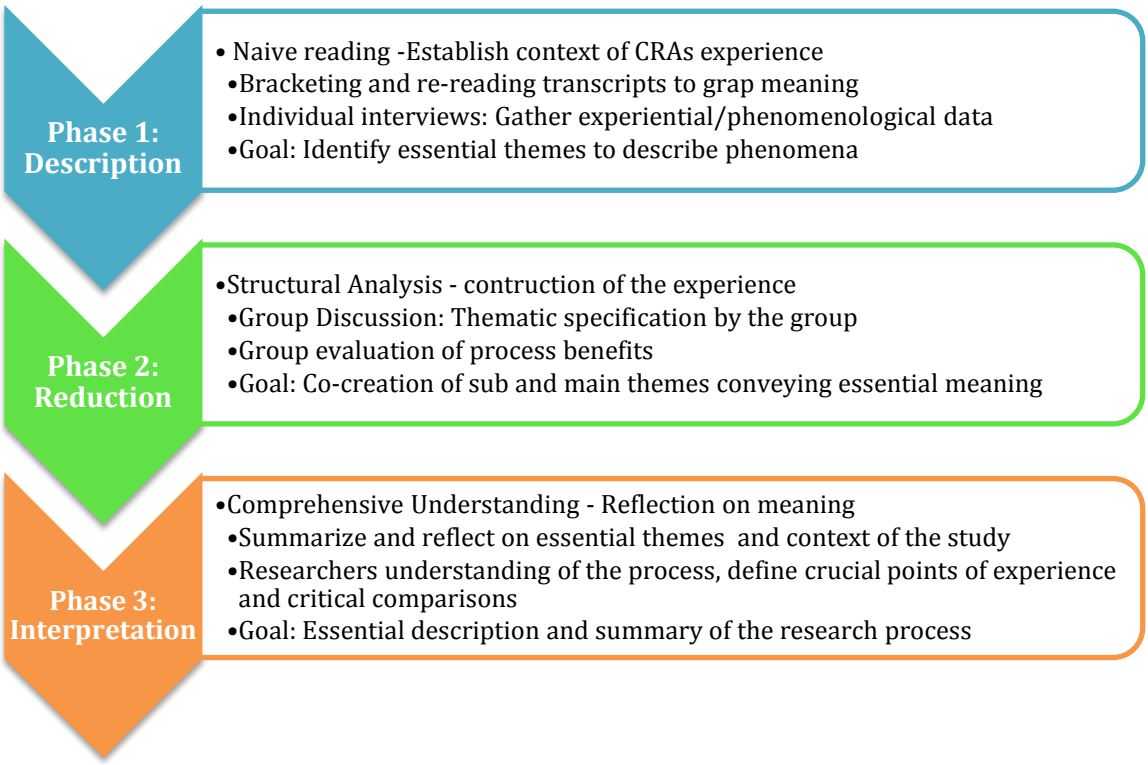


Figure 2: Study Design: Three Phase Interpretive Phenomenological Study (Flood, 2010; Seidman, 2012)

Considering that WLHA's experiences in HOPWA housing can potentially involve sensitive and personal subject matter (e.g. poor living conditions, medication, family life), I used individual interviews for initial data collection in Phase 1. This is also the key method of data collection within phenomenological methodology (Flood, 2010). A semi-structured interview guide (Drever, 1995) was used during the conduct of individual interviews. Semi-structured interviews are a flexible technique that allowed me to outline main questions in advance to set up a general structure or topics to be covered

(Drever, 1995) while still allowing the CRA the flexibility to guide in the reflection and clarification of their experience and the meaning and impact of housing services on their lives (Flood, 2010) (See Appendix A).

The analytical methods of interpretive phenomenological research have not been clearly documented within the literature (Benner, 1994; Chamberlain, 2009; Donalek, 2004; Flood, 2010; Moustakas, 1994), however, this method requires three key steps within the analysis of the interview transcripts: naïve reading, structural analysis and comprehensive understanding (Flood, 2010; Ricoeur, 1971) (See figure 2). Naïve reading in Phase 1 requires the researcher to engage with the data by reading and re-reading the transcripts to gain a preliminary understanding of meaning or highlights of the participants' experiences in relation to being a HOPWA beneficiary (Flood, 2010) and bracket a priori knowledge or assumptions. During structural analysis in Phase 2, the CRAs and I worked together during group discussion to identify meaning units, which are condensed main and sub themes, from the naïve reading in Phase 1 (Flood, 2010; Plunkett et al., 2013). During Phase 3, I used the IP process of reflecting and summarizing the essential meanings identified during the structural analysis in Phase 2, into a clear and concise description of the experiences of WLHA in HOPWA housing to achieve comprehensive understanding of their experiences (Becker, 2004; Donalek, 2004; Flood, 2010;

Zhou, 2010). Figure 3, depicted below, shows how the phenomenological results (analytical outcomes) from each phase informed the following phase of the study (Flood, 2010).

Phase	Focus/Objective	Instruments/Materials	Analyses	Phenomenological Result
1	Gather experiential/ phenomenological data in context of women's lives living in HOPWA housing	Individual Interviews using semi-structured interview guides; recordings of interviews	Transcription of interviews; identify natural meaning units (essential themes)	Description – essential themes to describe phenomena
2	Group Discussion –co-creation of key essential themes to understand the lived experience of WLHA in HOPWA housing	Phenomenological description from previous step	Group discussion; thematic specification by group participants; group evaluation of process benefits	Reduction – identify and condense essential themes into main themes and sub themes
3	Interpretative Phenomenological analysis	Materials from steps 1 and 2	Researchers critical understanding of the process; defining crucial points of experience; critical comparison (present group experiences to other data and relevant literature)	Interpretation – essential description and summary of phenomenological research process presented in everyday language

Figure 3: Three-Phase Interpretive Phenomenological Detailed (Flood, 2010)

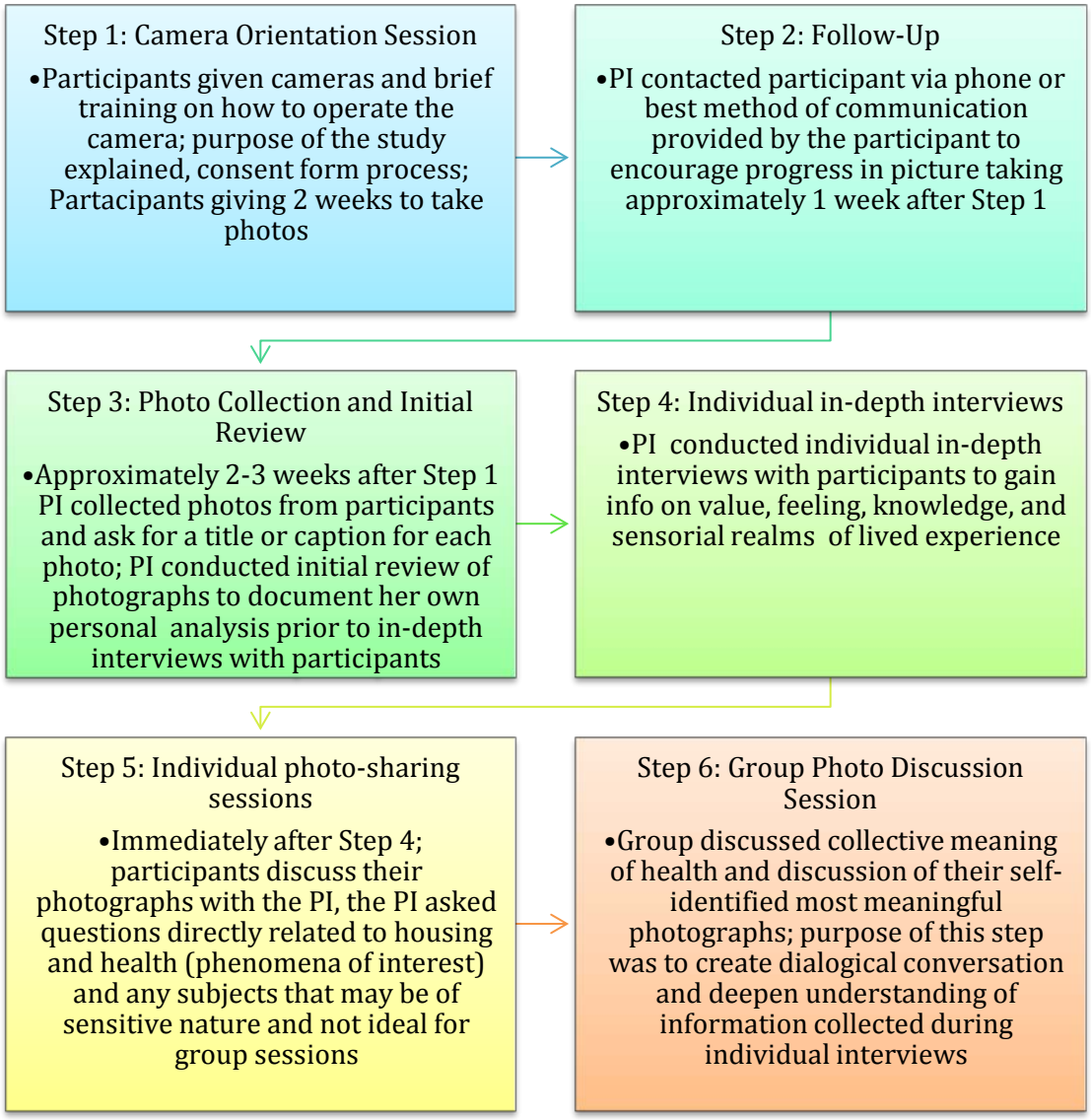
3.2.1 Photovoice

Photovoice is a critical element to this study's design. Photovoice is a participatory action research method, rooted in feminist theory that asks

participants to take photographs of their daily lives, selecting those most representative of their reality and experiences to discuss during individual and group photo discussions to gain a deeper understanding of their experiences and perspectives (Plunkett et al., 2013; C. Wang & Burris, 1997). This method has become a popular community development tool due to its integration of social action strategies and effective use when working with marginalized populations including WLHA (Gosselink & Myllykangas, 2007; Teti, Murray, Johnson, & Binson, 2012; Teti, Pichon, Kabel, Farnan, & Binson, 2013; C. C. Wang, 1999). Like other CBPR approaches, photovoice-informed research is notable for its ability to use community insights and perceptions into policy and program development (C. Wang & Burris, 1997). Moreover, it is a novel medium in its use of documentary photography to elicit a deeper understanding from the community vantage point (Plunkett et al., 2013). The visual and qualitative data collected through the process can capture rich data under the CRAs' direction, providing context, language and cultural understanding for the interpretation of their experiences (Teti et al., 2012; Teti et al., 2013; C. C. Wang, 1999). This element is unique to photovoice and provides the culturally grounded research that is lacking from the current HIV/AIDS housing literature. In addition to photovoice being a tool to identify the impact of housing on the lives of WLHA, this method also provided insight into the mechanisms of change found between

housing and potential positive health outcomes and fills an important void underreported in existing quantitative literature (Leaver et al., 2007) .

Researchers have also begun to use photovoice to collect phenomenological data (Cordova et al., 2014; MacMullen, 2013; Plunkett et al., 2013). Phenomenology traditionally relies on spoken language to understand experiences, but the use of photovoice data collection in phenomenological inquiry can provide a deeper understanding that cannot always be captured through spoken language alone (Plunkett et al., 2013). Using this multi-method approach to translate the experiences of WLHA utilizing HOPWA services into textual and visual forms constitutes a potentially innovative addition to housing research and findings in addition to being disseminated through various mediums (e.g., peer reviewed articles, print or web-based mediums) to inform HIV/AIDS housing research, policy and practice (Plunkett et al., 2013). This combined method can also be an empowering practice to the participants, who often are disempowered and stigmatized because of the intersections of their race, gender, class and HIV-status. I included a 6-step data collection process that incorporated the photovoice method to elicit phenomenological data (Plunkett et al., 2013). Figure 4 and section 3.2.2., shown below, illustrates how the photovoice data collection was woven into the IP inquiry process.



Steps 1-5 are associated with Phase I. Step 6 is associated with Phase 2 of phenomenological inquiry.

Figure 4: 6-Step Photovoice Data Collection Process in Phase 1 and 2 of Phenomenological Inquiry (Plunkett et al., 2013)

3.2.2 Overview of 3 Phase Process

Phase 1. Phase 1 included gathering experiential data in the form of individual interviews and photos taken, using photovoice methods to describe the essential themes of the phenomenon (Flood, 2010; Plunkett et al., 2013). During this step the CRAs: (a) attended a training session facilitated by the principal investigator (PI) and a professional photographer, to become oriented with the camera and the photovoice method; (b) returned two to three weeks after the training session to submit their photos and titles/captions for each photo for initial review by the PI before analysis; and (c) participated in an individual in-depth interview and subsequent photo sharing session with the PI to discuss sensitive and personal issues, and (d) share information about their experiences with housing services in DC (Plunkett et al., 2013). A semi-structured interview guide (Drever, 1995) was used to conduct a 30-60 minute individual interview with each CRA. (See Appendix A)

Phase 2. During Phase 2, CRAs participated in a group discussion of the themes they identified for thematic specification into main and sub-themes known as "meaning units" (Flood, 2010; Ricoeur, 1971). I used the photovoice method of group photo discussion to confer the collective meaning of HOPWA housing for WLHA (Plunkett et al., 2013). During the group discussion, the participants shared the photographs they found most meaningful, while also

sharing their reflections about the photovoice process and the individual interviews completed during the previous step (Plunkett et al., 2013). A semi-structured interview guide was used to facilitate the group discussion. See Appendix B for a description of the Group Discussion Guide.

Phase 3. Phase 3 involved the IP analysis of the qualitative data collected in steps 1 and 2 (Flood, 2010). I summarized the key themes and reflected on their relationship to the research question of how the HOPWA program in DC impacts the lived experience and health outcomes of WLHA. This analysis facilitated the development of an interpretation and definition of the lived experience of women living in HOPWA-funded housing. The details of the analysis are spelled out in Section 3.5.2.

3.3 Sampling Methods

3.3.1 Sampling Plan

A sample of WLHA was recruited from The Women's Collective (TWC), a community not-for-profit health and human service agency that provides support services to low-income WLHA in the District. I was invited to attend a women's support group meeting and a diabetes group meeting at TWC to introduce the project to potential participants. To adhere to HIPAA guidelines and protect the privacy of their clients, the group facilitators compiled a list of interested TWC clients and provided my contact information to those who

wanted to be screened for participation in the study. To recruit participants outside of TWC, I provided recruitment fliers (See Appendix C) to the Program Officer and Housing Program Specialist serving the HIV Housing Assistance Branch of the DC Department of Health Care, Housing and Support Services Division for distribution. I also provided recruitment fliers to a director at one of the DC-HOPWA grantee programs.

WLHA who were 18 years of age and older currently residing in HOPWA-funded housing or receiving HOPWA-funded residential support services in DC were eligible for the study (See Section 3.3.2 for eligibility criteria). All participants were screened via phone or in-person at TWC.

The study attempted to focus exclusively on WLHA receiving support services funded through the HOPWA program in DC. Since the study required camera operation and legal forms such as photograph release waivers (See Appendix H), I enrolled adult women who did not exhibit cognitive impairment, using the Folstein Mini Mental Exam (See Appendix J). Transgender women were also excluded from the study because their experience may be significantly different from cisgender women. All of the study materials were developed in English, so participants not fluent in English were excluded.

3.3.2 Population Inclusion and Exclusion Criteria

Inclusion Criteria

1. Biologically-born female
2. Age 18 and older
3. Currently receiving HOPWA-funded housing subsidies or services in the District of Columbia

Exclusion Criteria

1. Washington, DC HOPWA beneficiary for less than 30 days
2. Exhibit cognitive impairment determined by Folstein Mini Mental Exam (See Appendix J)
3. Not currently receiving HOPWA-funded subsidies or services including women on the waiting list for HOPWA services
4. English is not the prospective participant's primary language

See Appendix D for a copy of the study's screening tool.

3.3.3 Sample Size Calculation

Typically, photovoice projects report a sample size between 10 to 30 participants, with 7 to 8 participants recommended for group discussion (Catalani & Minkler, 2010; Cordova et al., 2014; Teti et al., 2012). WLHA are a marginalized community facing many physical, social and economic challenges

that may serve as barriers to their involvement during the course of a study (e.g. transportation, illness, childcare) (Teti et al., 2013). I attempted to recruit 12 participants to this study to allow room for attrition in the event that participants were lost to follow-up, and to ensure that there would ultimately be at least seven participants in the context of group discussion.

3.4 Measurement Plan

3.4.1 Data Collection

The bulk of the data was collected in a conference room at TWC. One individual interview was conducted at the participant's local library in a private meeting area. Data were in the form of CRA photo visual data, CRA narrative qualitative data, and quantitative data collected from a brief demographic survey (See Appendix C) given to CRAs at the photovoice training session. This demographic data helped characterize the sample during the data analysis. Each CRA was given a VistaQuest VQ1024 Digital Camera to collect visual data. Digital recorders were used to collect CRA narratives during individual and group photo discussion meetings. All of the CRA sessions were recorded and transcribed by the PI, or trained research assistants. Photo releases approved by Drexel University were also collected for any photos that CRAs planned to use for exhibits or public display.

3.4.2 Photovoice Training

During the first group meeting after consent and enrollment, I facilitated photovoice training, for the CRAs. The photovoice training included instruction on the basics of the photovoice process, how the data from the process would be used, as well as legal and ethics training. This training was essential to ensure that all CRAs were fully informed about the process, what would happen with their pictures, and which forms they needed to complete for their photos to be used in any publications or public display outside of the study's group discussion. This part of the training was completed prior to the distribution of the cameras. I led the training session with the technical assistance of a professionally trained photographer. Handouts used as training aids can be found in Appendix F.

3.4.3 Camera Instructions

A professional photographer and I trained the CRAs on basic camera use. This training covered how to operate the camera, useful camera features (i.e. zoom, flash, modes), camera angles, and how to capture their photographs (i.e. framing, texture and composition). We also suggested how to capture pictures of sensitive subjects to avoid ethical or physical threats. The professional photographer taught basic photography techniques including but not limited to basic camera operation, lighting and staging. Camera training also included a

"Photo Game" activity where participants were given an opportunity to apply and practice the skills taught during training. Handouts used during the photovoice training can be found in Appendix G.

3.4.4 Incentives

CRAs were allowed to keep their camera and accompanying accessories (i.e., memory card, USB cord). CRAs were also given a $20 cash incentive for each photovoice session that they attended, including the training sessions and individual and group discussion sessions.

3.5 Data Management and Analysis Plan

3.5.1 Entering and Securing Data

During each photovoice discussion session, photos and audio data were transferred from the electronic devices (CRA cameras and audio recorder) onto a study-designated laptop. From the laptop, the data were uploaded onto a private research cloud storage space maintained by the George Washington University (GWU), where I am employed. The research cloud is a file management database that is password-protected. This upload was conducted within 24 hours of each discussion session. Subsequently, all files were accessed and imported into NVivo 10 qualitative analysis software, also operated via the mentioned password-protected research cloud. Additional qualitative data in the form of transcripts and field notes were also stored on the private cloud research

space. Quantitative data from the demographic survey was stored in the PI's private office at GWU in a lockable file cabinet. Quantitative data were entered into SPSS 24 software, provided via the research cloud, for analysis of descriptive statistics (i.e. frequencies, means, modes, medians) and stored on the private research cloud storage space as well.

3.5.2 Analyzing Data

I analyzed the visual and audio qualitative data from the individual and group photo discussions using techniques outlined in interpretive phenomenology (Ricoeur, 1971) and Plunkett, et. al.'s (2013) photovoice-phenomenological inquiry method . The three-step analytical process includes: (1) naïve reading of the transcripts, bracketing and viewing of the photographs; (2) structural analysis to identify main and sub-themes through co-creation with the CRAs using photos, captions and themes from Phase 1; and (3) comprehensive understanding by the PI to summarize and reflect on the key themes in relation to the research question, naïve reading, field notes and memos (Flood, 2010; Ricoeur, 1971).

During the third step of comprehensive understanding, I followed Smith, et al.'s (1999) IPA guidelines to ensure that this step was completed thoroughly and systematically. First, I focused on the transcripts, printed out hard copies, and read and re-read these numerous times, and noted potential themes, codes

and general memos in the margins. I read in-depth each transcript individually in order to construct memos about themes found within the narratives. Using my memos and a priori knowledge and assumptions about housing services in the District that I logged in during bracketing in Phase 1, I developed a codebook. My initial codebook was produced manually, and included main themes related to "experiences with housing," "health impact" and "HOPWA." I used line-by-line coding to identify main and subordinate themes in the relevant text.

Quantitative data from the demographic survey were entered into SPSS 24 to generate descriptive statistics about the characteristics of the study sample.

3.5.3 Bridging Theoretical Frameworks

During my analysis, I found the SEM to be too broad to interpret the relationship between the physical and social environment of the women's neighborhoods, social-structural factors such as power and privilege, and their association with race, gender and class, and how these factors impacted the CRAs' health. I adapted the Urban Health Framework (UHF) (Galea, 2005) in order to help interpret how the built environment and social environment impacted the CRAs' health. The UHF enabled a deeper understanding of how the context of urban living (e.g. built environment, access to green space, social disorganization, segregation and inequality) relates to health, and the

mechanisms that may explain this relationship (Galea & Vlahov, 2005). The Intersectionality Framework (Bowleg, 2012; Collins, 1993; Crenshaw, 1991) aided in my reflection and interpretation of how the CRAs' multiple social identities (e.g. race, gender, class and HIV status) intersect with social-structural factors including power and privilege related to housing programs and policies, and how the multiplicity of these influences shaped their experiences with housing services. Because intersectionality focuses on the viewpoint of marginalized populations (Bowleg, 2012), it facilitated the analysis of data collected via photovoice methods. Moreover, bridging the two analytical frameworks helped me reflect about and interpret the relationship of the identified themes, and provided a more comprehensive understanding of WLHA's experiences of HIV/AIDS housing services in DC, and their impact on their health.

3.6 Scientific Rigor

Trustworthiness of Analysis. Trustworthiness of analysis speaks to the provision that a qualitative researcher takes in order to make sure that their study is academically sound (Shenton, 2004). I used four strategies to evaluate and uphold trustworthiness of my analysis: (1) credibility; (2) transferability; (3) dependability; and (4) confirmability.

Credibility provisions try to ensure that the study findings are congruent with reality. To ensure the credibility or confidence in the truth of study

findings, the CRAs provided titles, captions, themes and clarification on meaning. This helped promote authenticity in my interpretation during analysis (Plunkett et al., 2013) and appropriate representation of the CRAs experience. I also had prolonged engagement with the site, TWC, CRAs and key stakeholders involved in HIV/AIDS housing to help me develop a familiarity with the CRAs and the organization prior to data being collected (Shenton, 2004). Another strategy I used to establish credibility is triangulation, which involved using different methods of observation including individual and group interviews, and CRAs' photographs. Reflexivity and the researcher's background or qualifications are another strategy for establishing credibility. I kept a reflexive journal throughout the study in order to record my initial impressions, reflections on the process, and other assumptions and prior knowledge. In regards to my background, I serve as a senior level researcher at the GWU's Department of Psychology, and have more than seven years of combined experience in conducting community-based research, HIV prevention and intervention research, risk behavior research with Black heterosexual men, mixed-methods and photovoice research with WLHA. This experience was critical for the development and success of the project. Also, as a member of the DC Department of Health HIV Prevention Planning Group, I had insight about how HOPWA operates as a funding resource for housing in the District. This

context was part of my a priori assumptions that I outlined during bracketing, and my analysis of the CRAs' experiences with HIV/AIDS housing services.

Transferability relates to the researcher's responsibility to give detailed information on the context of the study. I established transferability by providing a clear description of the context, participant characteristics, and data collection and analysis methods (Plunkett et al., 2013).

Dependability addresses the reliability of the study, where it is important to give specific details on the research process and context so that if it were repeated, other researchers would have similar results (Shenton, 2004). To promote dependability, I kept detailed analytic memos throughout the process and discussed my analytic decisions with another doctoral student researcher with experience with IP, to continuously reflect on the process and my interpretations. (J. A. Smith, Jarman, & Osborn, 1999).

Lastly, confirmability addresses the steps taken by the researcher to ensure that the interpretations and findings are reflective of the participants' experiences and not the researcher (Shenton, 2004). To ascertain confirmability, I described my research methods and procedures in extensive detail and kept a reflexive journal— a personal account about what informed my methodological decisions, perspective and learning experience—during the course of the study. I

also used multiple theoretical perspectives, SEM, UHF and intersectionality, to examine and interpret the data to achieve theoretical triangulation (Patton, 1999).

3.7 Ethical Issues

The study protocol was approved by Drexel University's Institutional Review Board to ensure all policies related to ethical research were met (See Appendix K). This included but was not limited to human subjects research certification, HIPAA certification, and consent forms (See Appendix L) signed by all CRAs. I also worked with Drexel University to develop photo release waivers, which were signed by CRAs and any individuals identifiable in the photographs (see Appendix D). Only photos accompanied by the appropriate photo waivers are included in this dissertation and any potential future publications or presentations to be included during the dissemination of the study's findings. Photographs featuring identifiable non-waivered individuals were used for data analysis only, and will not be used in any public or academic displays of this study. During training, CRAs were also thoroughly trained in photovoice, photography techniques, and ethics. CRAs were not required to have identifiable photographs of them featured in any of the dissemination materials or presentations, although all participants signed waivers to allow photos of them to be used during the study's dissemination. The CRAs selected and approved all pictures used during the dissemination of findings.

3. 8 Handling Barriers to Conducting Research

One of the potential barriers regarding this research was attrition. The sample size within photovoice and qualitative research is typically small, and the process required multiple meetings with CRAs for training and photo discussions. This combination of small sample size and the need for multiple visits increased the potential for attrition. To diminish attrition concerns, I asked CRAs to provide contact information to facilitate scheduling visits (See Appendix E for Contact Information Form). I used emails, phone calls, text messages and announcements via TWC staff to stay in frequent communication with the CRAs, particularly during data collection and analysis. In addition, all of the CRAs were clients at TWC, so all data collection and training sessions were scheduled at that site to help reduce transportation challenges. In the event that CRAs could not come to TWC, I met them at a place conveniently located for them (i.e., local library or other HIV/AIDS service provider's office).

Funding for the project was also a potential barrier to the study's design. I developed a GoFund Me campaign to raise $770 to cover incentives and the partial cost of camera equipment. All GoFund Me donors were sent a photo selected by the participants to thank them for their support. I used self-funding, volunteer services and trained research assistants to cater the group meetings and assist me with transcription.

Lastly, during data collection, two participants were prohibited from activities at TWC for reasons unrelated to the study. Consequently, the two CRAs were unable to attend the group photo discussion. I met with both women individually outside of TWC property, to share and discuss the photos and themes identified by the group during the session they missed. This allowed me to obtain their feedback and input on the group's experiences. However, they did not have the opportunity to share their photos with the group.

CHAPTER IV: RESULTS

4.1 Approach

The purpose of this study was to investigate the experiences of a sample of women receiving HOPWA funded services in Washington, DC in 2016. During the conception of the study, the Social Ecological Model (SEM) served as a conceptual framework for guiding its focus (See Section 2.3). During the implementation of the study, I subsequently found it important to apply the Urban Health Framework (UHF) and Intersectionality Framework to aid in the interpretation of my research analysis. Initially, the SEM outlined the complex interplay of individual, community and structural factors that helped shape WLHA's experiences with housing. However, during the analysis phase, I found the model to be too broad to identify mechanisms linking housing to health for low-income adult Black women, specifically. For this reason, I adapted the UHF (See Section 3.5.3) to explore the mechanisms linking housing and health within both environmental as well as situational contexts. Lastly, I used the Intersectionality Framework (See Section 3.5.3) given its capacity to link the role of social-structural context and its effects on multiply marginalized populations, to more fully understand how policies, power structures and discrimination influenced women's experiences and perception of HIV/AIDS housing services.

I have organized the study's results into two sections. The first section presents findings related to the key objectives sought (See Section 4.3): (a) knowledge of HOPWA and other housing services; (b) the process of acquiring stable housing; (c) the physical and social environment of housing and its impact on health; and (d) an assessment of how the District is meeting the housing service needs of WLHA. Other findings related to participation in the photovoice process are covered in the following section (See 4.4).

Originally, I aimed to explore how WLHA's housing experiences were directly related to HOPWA-funded housing and services. During the conduct of the screening process (See Appendix D) and administration of the quantitative survey (See Appendix E), I provided clarification to the CRAs on all HOPWA-related terms and services. Yet, only two of the nine CRAs reported having heard the term HOPWA before their participation in the MTS project, and only one CRA confirmed receiving HOPWA-funded permanent housing assistance at the time of data collection. None of the CRAs asserted having a clear understanding of exactly what the HOPWA program entailed, and how its funding mechanism worked (See Section 4.3.1).

Given that the women in the study weren't familiar with HOPWA, it was not perceived by them to be a salient influence on how they experienced housing. Furthermore, only X of nine women obtained housing through

HOPWA. Consequently, my interpretations in the study focus on HIV/AIDS housing services in the District as a whole, and are not solely focused on services funded by HOPWA. I made this analytical decision to avoid mischaracterizing the HOPWA program, and to give an accurate interpretation of women's experiences with housing services in the District. In the Results section, I used the general term "housing services" to reference any housing or related services that CRAs experienced, accessed via District HIV/AIDS service organizations and providers. Only in instances where the CRAs explicitly referenced "HOPWA" was the term used. This sought to ensure that I accurately described the women's experiences and thus avoid using the term HOPWA to describe all experiences with housing services in the District. A discussion of the implications of the women's unfamiliarity with the HOPWA program is provided in the Discussion section (See also Section 4.3.1).

To accurately portray the experiences of the participants, I have included their verbatim quotes, including minor edits only when necessary to improve clarity. Additionally, the study's images are presented with the exact captions and accompanying narratives provided by the CRAs, when appropriate. I use pseudonyms for all participants and names mentioned within the quotes in order to protect confidentiality.

4.2 Overview of Participants

Table 1, shown below, presents the demographic characteristics of the participants ($N = 9$). I screened a total of 16 women for MTS and 13 of them were deemed to be eligible. The study enrolled 10 women; however, one woman withdrew immediately after the camera training due to cognitive impairment and relocating from the District. Only demographic data were collected from the withdrawn participant, but this information was not included in the analysis.

All of the MTS CRAs self-identified as African American mothers, with a mean age of 48 (See Table 1). More than half of the women were unemployed and/or receiving some form of supplemental/disability income. While the sample's participants did not include residents from Wards 2 or 3—the two wealthiest of the eight wards in the District—all four quadrants of the District were represented (See Table 2). Each CRA reported receiving direct housing assistance (i.e., housing or rental assistance), and eight of the nine CRAs also reported receiving housing-related supportive services (e.g., case management, mental health services).

Table 1

Participant Demographic Characteristics (N = 9)

Age	Mean (SD)	Range
	48.2 (6.53)	35-56
	n	(%)
Ethnicity		
Black/African American	9	(100%)
Marital Status		
Single	7	(77.8%)
Married	2	(22.2%)
Education		
Some high school	2	(22.2%)
High school graduate/GED	1	(11.1%)
Some junior college or vocational school	4	(44.4%)
Associate degree	1	(11.1%)
Graduate degree	1	(11.1%)
Income		
<$10,000	4	(44.4%)
$10,000-$19,999	2	(22.2%)
$20,000-$39,999	1	(11.1%)
Declined to answer	2	(22.2%)
Employment status		
Employed full-time (≥ 30 hours/week)	1	(11.1%)
Employed part-time (≤ 20 hours/week)	2	(22.2%)
Unemployed	6	(66.7%)
Receiving supplemental income (SSI, SSDI or IDA)	7	(77.8%)
# of children		
1-2	5	(55.6%)
3-4	3	(33.3%)
>4	1	(11.1%)

Table 2

Participant Housing Characteristics (N = 9)

	n	(%)
DC Ward (Quadrant)		
Ward 1 (NW)	1	(11.1%)
Ward 4 (NW)	2	(22.2%)
Ward 5 (NE)	2	(22.2%)
Ward 6 (SW)	1	(11.1%)
Ward 7 (NE)	1	(11.1%)
Ward 8 (SE)	2	(22.2%)
Type of Housing		
House/apartment you pay for	6	(66.7%)
House/apartment someone else pays for	3	(33.3%)
Housing Assistance Received		
Tenant-Based Rental Assistance	3	(33.3%)
Single Room Occupancy	1	(11.1%)
Project-based Unit Housing	3	(33.3%)
Home Purchase Assistance Program	1	(11.1%)
Other (unspecified)	1	(11.1%)
Housing Supportive Services Accessed		
Adult day care/personal assistance	2	(22.2%)
Case management/client advocacy	4	(44.4%)
Education	1	(11.1%)
Employment assistance/training	1	(11.%)
Health/medical/intensive care services	2	(22.2%)
Legal services	1	(11.1%)
Mental health services	3	(33.3%)
Transportation	2	(22.2%)
Time at current residence		
3-6 months	1	(11.1%)
More than a year	8	(88.9%)
	mean	(range)
Years living in current neighborhood	9.4	(1-20)

4.3 Findings Related to Research Aim

I structured the study's results into four key aspects of the CRAs' experiences with housing services:

1. Knowledge of HOPWA and housing services.

2. Process of acquiring stable housing.

3. Physical and social environment of housing and its impact on health.

4. District's capacity meeting the housing needs of WLHA. .

As part of the IP process, all of my interpretations were based on a comprehensive review and analysis of photo images, participant narratives, individual and group discussion transcripts, bracketing, my prior knowledge, and field notes. I have included a diagram to depict how the different sources of data guided my interpretations (See Appendix M)

4.3.1 "We didn't know nothing about it": What women know about HOPWA and Housing Services in the District

During the study's screening process, administration of quantitative surveys and individual and group discussions, CRAs requested further clarification on both the meaning of the term HOPWA and services it funds (e.g., tenant-based rental assistance, project-based housing, etc.). During the group photo discussion, only two women raised their hands when I asked the group who was familiar with HOPWA prior to their participation in this study.

Mickey, a 48-year-old woman living with her son and grandchild in project-based housing in Ward 8, spoke for the group and stated, "I heard of [HOPWA] but we didn't know nothing about it." Despite a few having heard of the term, the CRAs agreed that they "don't know what it [HOPWA] can help us with."

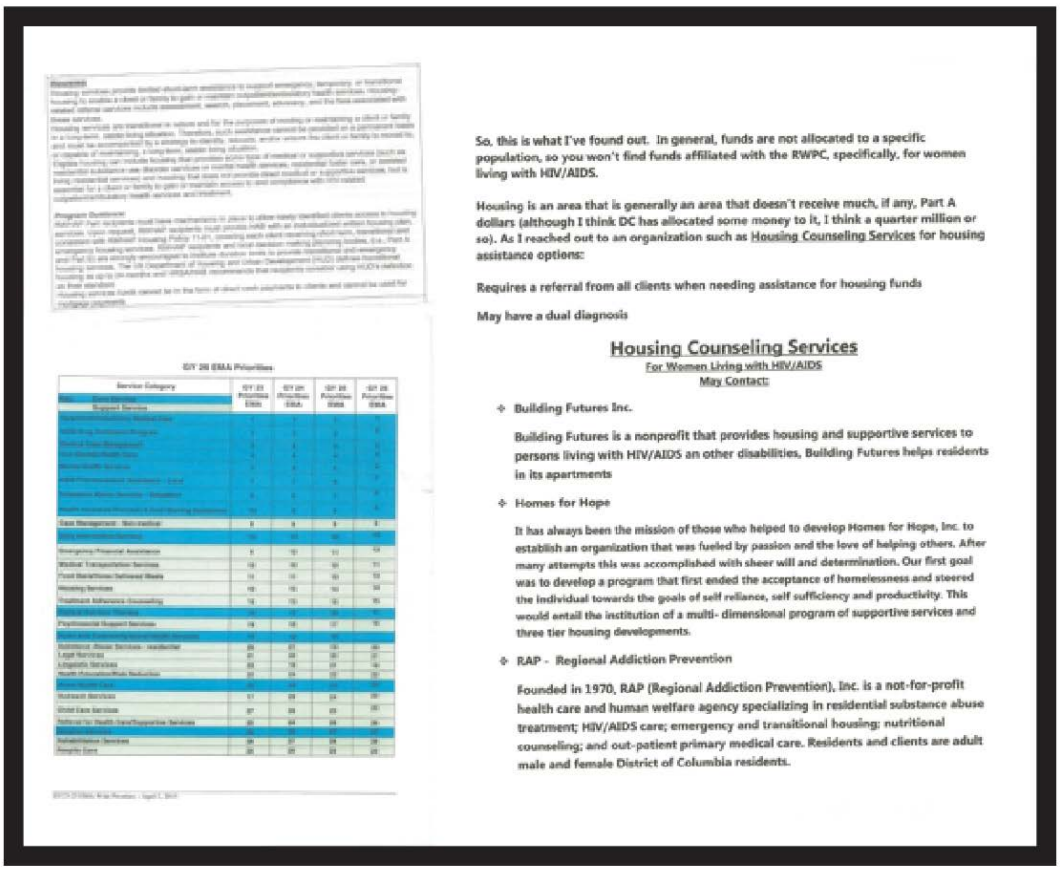
While the women were generally unfamiliar with HOPWA, all of the CRAs reported receiving some form of housing services in the District during the study's screening and data collection phases. I also confirmed that the CBOs and programs that provided support services to the CRAs were receiving some form of HOPWA funding. While the lack of knowledge of HOPWA would suggest that the CRAs did not receive any HOPWA-funded services, this was not the case. Rather it speaks more to the co-mingling of funding that the DC Department of Health (DOH) uses to provide housing support to homeless residents including PLHA (HAHSTA, 2012).

Through various HIV/AIDS service organizations and programs, CRAs were linked to shelters, transitional housing, income subsidies such as SSI and SSDI, housing-related services and HUD funded housing options. Mickey, one of the two CRAs familiar with the term HOPWA, was the only participant that confirmed receiving permanent housing services in the form of tenant-based rental assistance through a HOPWA-funded provider. Out of the remaining eight participants, four acquired their current housing unit through Section 8

Housing Choice Vouchers, one purchased a home through another HUD-funded program, and for three of them I could not confirm whether their single room occupancy (SRO) or tenant based rental assistance (TBRA) were HOPWA funded units.

Eris, the CRA who purchased her home through another HUD program, was surprised that as a Ryan White Planning Council[1](RWPC) member, she was unfamiliar with HOPWA. She used her participation in this study as a catalyst to gather information to educate the group and herself on the program. Eris's "journey to look and see what we could find" about HOPWA funding in the District uncovered, "There are three referral facilities [that] assist women with HIV and housing." Eris created what she called a "Survival Guide" (See Image 1) which included photos of DC DOH documents showcasing HIV/AIDS service funding priorities and a collection of her research notes and pamphlets. Eris felt that the scarce housing services for WLHA and the lack of knowledge by the CRAs of HOPWA spoke to a larger issue that the DOH "stopped thinking we [WLHA] needed help."

[1] Ryan White Planning Council: Planning body for HIV/AIDS services and the DC metropolitan area. The council is comprised of PLWH, providers, advocates and government officials and ranks HIV/AIDS service priorities and determines funding allocations



So, this is what I've found out. In general, funds are not allocated to a specific population, so you won't find funds affiliated with the RWPC, specifically, for women living with HIV/AIDS.

Housing is an area that is generally an area that doesn't receive much, if any, Part A dollars (although I think DC has allocated some money to it, I think a quarter million or so). As I reached out to an organization such as Housing Counseling Services for housing assistance options:

Requires a referral from all clients when needing assistance for housing funds

May have a dual diagnosis

Housing Counseling Services

For Women Living with HIV/AIDS

May Contact:

- Building Futures Inc.

  Building Futures is a nonprofit that provides housing and supportive services to persons living with HIV/AIDS an other disabilities, Building Futures helps residents in its apartments

- Homes for Hope

  It has always been the mission of those who helped to develop Homes for Hope, Inc. to establish an organization that was fueled by passion and the love of helping others. After many attempts this was accomplished with sheer will and determination. Our first goal was to develop a program that first ended the acceptance of homelessness and steered the individual towards the goals of self reliance, self sufficiency and productivity. This would entail the institution of a multi- dimensional program of supportive services and three tier housing developments.

- RAP - Regional Addiction Prevention

  Founded in 1970, RAP (Regional Addiction Prevention), Inc. is a not-for-profit health care and human welfare agency specializing in residential substance abuse treatment; HIV/AIDS care; emergency and transitional housing; nutritional counseling; and out-patient primary medical care. Residents and clients are adult male and female District of Columbia residents.

"Survival Guide" by Eris

Image 1. Housing Services

Even with HOPWA providing housing information to more than 10,000 PLHA each year (Department of Housing and Urban Development, 2017), the CRA's knowledge and experiences with housing assistance primarily revolved around shelters, transitional housing and Section 8 housing funded by other

sources . I will discuss the implications of the women's lack of knowledge about HOPWA in the discussion section (See Chapter 5).

4.3.2 "We had to go through hell to get it": Experiences acquiring stable housing

All of the women shared similar stories of long term homelessness, with two CRAs disclosing they were homeless for a decade or more. They described "going through the mud" in order to get housing assistance, oftentimes waiting years to get stable units, and sometimes receiving none. Mickey, who initially accessed HIV/AIDS services more than 12 years ago, felt that "[Back] then all they did was help with emergency assistance and stuff like that."

While Mickey spoke about the limited housing opportunities a decade ago, the other CRAs felt the current housing opportunities were just as limited. Ayana, who was homeless for more than 10 years, summed up the current housing assistance climate in the following way: "They ain't giving no housing!" Many of the CRAs were single, older Black women whose children did not live with them. CRAs stated that their single status and lack of dependents limited their housing assistance opportunities. Mickey elaborated on the current process for acquiring stable housing through housing services by stating:

> It's a process. You're homeless; you go from there to transitional, from transitional to SROs, to where ever until you get into your place. But

nowadays—from a shelter to a friend's house is what's going on because ain't nowhere for us to go.

Mickey described a pipeline from shelters to transitional units to stable housing, which truncated at securing transitional housing due to a lack of available stable units. CRAs discussed the existence of a waitlist of PLHA seeking housing that was closed to new applicants because of the DC Housing Authority's inability to meet the housing needs of thousands of applicants still on the list. Mickey's claim that there was "nowhere for us to go" was based on her own experience of being on the list for 21 years. After 11 years of waiting, she was able to acquire stable housing through Section 8, despite still being on the list for PLHA for another decade. For the women, this list was merely a formality and not a viable avenue for obtaining housing, as none of the women reported getting housing from being on the list. Mickey summed up the experience of being on the list by saying, "People have been on that list for that long and still have not been placed. If you didn't get it, you haven't gotten it, and you won't get it. "

In addition to limited housing opportunities and lengthy waiting times to secure assistance, the laborious process of securing stable housing was compounded by discriminatory qualification standards. As previously stated,

women suggested that their single status and lack of dependents limited their ability to qualify for certain housing programs or opportunities. After receiving housing referrals and Housing Choice Vouchers, CRAs also experienced economic discrimination including being subjected to credit checks by private property owners who accepted these forms of housing assistance. Kim, a 41-year-old living with her partner in a Section 8 apartment, described the burden of having to prove her capacity assuming financial responsibility via credit checks as a low-income woman seeking affordable housing assistance:

> Even if you have a housing choice voucher or some type of program they want to do credit checks and all kinds of stuff now. And if your credit ain't good… because I know my credit ain't A-1 [good credit]. Most places want you to do a credit report. The police background isn't even the hard part. The hard part is the credit report. You know because if I'm on a housing choice voucher than you should know that…9 times out of 10, my credit is not top notch.

The District's Housing Choice Voucher is a federally-funded program that provides rental assistance to low-income families, the elderly and the disabled. Beneficiaries can use this voucher program for apartments or houses in instances involving a willing prospective landlord, including subsidized housing projects. However, as exemplified by Kim's experience, private property owners and

management that accept theses vouchers set their own qualification criteria. This allows property owners to apply middle-class standards to assess the prospective tenant's capacity for fiscal responsibility, a challenging proposition for low-income applicants who often lack the same class privileges.

Monica, a 50-year-old single woman living in an apartment provided by a HOPWA grantee in Ward 4, described a unique experience where despite having HOPWA-funded TBRA, a referral and ability paying a security deposit, she was denied an apartment. As a Black woman applying for a unit in a housing complex and neighborhood that is majority Latino occupied, she perceived the denial as being racially motivated. Furthermore, as an individual already facing economic hardship, unable to afford security deposits, and lacking transportation to a housing complex, this process often represented a significant burden without assurances of a stable place to live in the end. This experience caused Monica to question not only the motivations of the property manager, but also those of the case manager and the HOPWA-funded program that referred her.

Monica saw herself and the other CRAs as "survivors"; survivors of the disease as WLHA, of the streets as formerly homeless individuals, and survivors of the housing services process. She explained:

> Nine times out of 10, a lot of us had to go in shelters, then it was transition. We didn't jump from A to B. You gotta' go through the mud the same way we did. We didn't just get it like that. We had to go through hell to get it.

The process of navigating housing services was "hell" for the CRAs. Even from the initial stages of the emergency shelter to a stable housing pipeline, the CRAs' gender, class and marital status often restricted their already limited access to affordable housing. Housing service programs in the District were generically designed, and did not take into consideration the specific social locations of disadvantaged, Black, and poor WLHA.

4.3.3 "I feel like I'm in a prison": Housing environment's impact on health

For eight of the study's nine participants, the physical and social environment of their housing unit and neighborhood was a major focus of their photo shoot backdrops and discussion. Eris, the participant who purchased her home through a HUD program and who took photo images of housing services information, was the only participant who did not discuss the physical and social environment of her home.

Physical Environment. CRAs experienced exposure to hazardous living

conditions, including deteriorating structures, leaks, mold and pests (e.g., vermin and insects) within their individual units and common areas of the housing complex (e.g., laundry rooms, courtyards, stairwells, etc.). Brandy, a 50-year-old woman living with her boyfriend and 19-year old son in Ward 5, described the severe mold problem in her Section 8 apartment in the following way:

> They [property management] tell me to throw bleach on it [mold] and every time I put bleach on it, it comes back. The lady upstairs, she got mushrooms out it's so much mold. My son says "Mom, put bleach on that." But it comes right back. You know, it's in the walls; it's on the windowsill, in the bathroom.

While Brandy experienced one of the more extreme hazardous exposure cases amongst the CRAS (See Image 2), all of the women acknowledged that the exposure to mold and pests was a direct threat to their physical and mental health, as well as the health of their family members. Women said that they found themselves stressed, depressed and angered as a consequence of their sub-standard living conditions. For Brandy, the exposure led to hospital visits and exasperated her son's asthma. Eventually, her family was forced to split-up, and to seek shelter at different friends' homes in order to avoid further exposure. Consequently, the exposure not only had health implications, but also caused financial strain for Brandy and her family, as she struggled to pay rent at her

uninhabitable apartment and at friends' houses where she and her family sought shelter.

Image 2. Physical Environment

As highlighted in Brandy's account, property management was often unresponsive to the CRAs' maintenance requests. The women described relentlessly cleaning to get rid of mold and avoid being perceived as "dirty" by guests visiting their home. Some CRAs reported having hazardous structural problems, and that management was unresponsive to their maintenance requests

or left the requests unresolved for periods longer than a year. Monica was one of six CRAs who photographed structural damage in their units; in her case, holes caused by a leak that lasted “more than 30 days”, and went unanswered even after notifying management. Her response to the unanswered major maintenance request was “What could I do?" Outside of reporting problems to management, CRAs expressed feeling that they had few options when addressing hazardous living conditions. In response, some CRAs resorted to ignoring structural issues that they perceived “didn't directly affect them” (e.g., structural hazards on the property grounds, but not within their own unit). The women described relocation as an unfeasible option due to the same discriminatory practices related to gender, class, marital status, and sometimes race that they view as critical barriers to acquiring the needed housing.

Housing services programs including HOPWA and Housing Choice Vouchers have minimum standards of habitability that housing units must meet: decent, safe, and sanitary. Yet, none of the CRAs reported any sort of evaluation or inspection regarding the quality of their homes. Without the support of the property management, built-in quality control checks by housing services and minimal likelihood of relocation, a majority of the CRAs were denied habitable living conditions, and as a result often faced their social support being threatened or limited. Specifically, their loved ones were often either unable or

open to visiting or living with them due to the physical condition of their homes.

Conflict. Despite exposure to hazardous living conditions and related negative health outcomes, CRAs also provided counter-narratives relative to the physical condition of their housing. For example, despite the substantial problems with the structural conditions of their units, several women noted that their homes were sources of pride and stability, and were sometimes even health promoting. After describing long stints of homelessness, some of the women still said that they "loved" their apartments because it was a space of their own, and also provided stability for their families. Ayana discussed this sentiment after experiencing more than a decade of homelessness and trauma related to childhood physical, emotional, and sexual abuse by her relatives. Having her home allowed her to connect with her boyfriend and friends by hosting gatherings, such as a fish fry, and strengthening her social support with what she called her "real family," presumably her family of choice.

Image 3. Social Support

CRAs also noted that they found that having stable housing aided their ability to sustain behaviors critical to maintaining their health as WLHA. When asked how her housing related to her health, Simone, a 48-year old woman receiving tenant-based rental assistance for an apartment in living in Ward 6 explained:

> Without stabilization I wouldn't be able to do that [adhere to medication]. I couldn't take all these meds because I would be too worried about eating. How you going to eat if you don't have anywhere to take meds? You won't be able to get stable because you can't do all that. You'll just be

all over the place. You'd just be worried about a place to stay —A place to lay your head.

Simone's statement suggests that having four walls and a roof did help her practice health promoting behaviors, such as taking her medication, eating a balanced diet, and going to doctor's appointments.

Despite the women's counter-narratives about housing's positive impact on some health behaviors, the false economy of housing services should not be overlooked. In theory, housing services programs aim to link WLHA with safe and sanitary housing as well as supportive services to improve health, health behaviors, while diminishing costs for health services such as hospital visits (Lisa said cite). Ironically, the CRAs' experiences with hazardous exposure within their units documented by this study, led to additional healthcare and housing costs, as well as physical, mental and emotional stressors.

"Stable and Healthy" by Simone

"Without stabilization I wouldn't be able to do that [adhere to medication]. I couldn't take all these meds because I would be too worried about eating. How you going to eat if you don't have anywhere to take meds? You won't be able to get stable because you can't do all that. You'll just be all over the place. You'd just be worried about a place to stay —A place to lay your head." (Simone)

Image 4. Health Impact

Social Environment. While five CRAs photographed images of their individual housing units, eight of the nine CRAs focused on taking pictures of their neighborhoods instead. Monica stated, "When I was taking pictures of my apartment and things, I started getting fucking depressed." She opted to venture outside of her house but she still, "Didn't really find any beauty in [her] neighborhood." She described going out of her way to photograph things she found beautiful in her neighborhood, such as trees that she never noticed (See Image 5). In pursuit of finding "beauty" or positive aspects of their social

environment, four CRAs photographed green space such as trees and parks, and one participant photographed a family fish fry at her home.

Outside of this handful of photos, the women mainly discussed the complexity of the social environment of their apartment buildings, housing developments, and neighborhoods more so than the physical structures. Most of this discussion revolved around spatial segregation and inequality caused by gentrification, social disorganization, and informal social ties that impacted the CRAs' experiences with housing, both positive and negative.

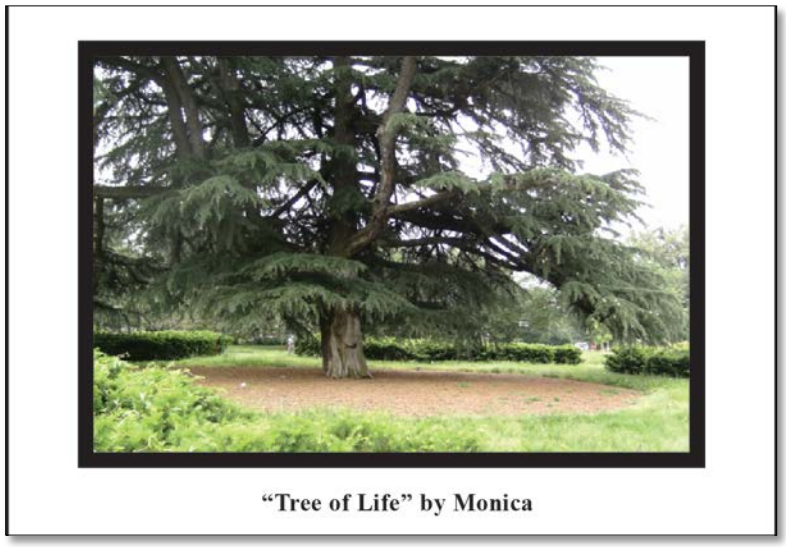


Image 5. Green Space

Gentrification. Within the District, gentrification has been described as the "influx of new white residents" and the associated economic investment in

neighborhoods that are economically distressed (Sturtevant, 2014).

Gentrification was the most salient theme in the CRAs' photos and discussions. The CRAs expressed notable concern for the racial and economic divide accompanying the gentrification within their neighborhoods in the District. Rapidly transforming the built environment (e.g., new buildings, businesses, and parks), gentrification also drove up already expensive housing prices and attracted middle- and upper-class White residents to the previously predominantly Black low-income neighborhoods. Angel, a 35-year old who recently lost her single room occupancy in Ward 5 due to an arrest, reflected on her old building located adjacent to TWC offices:

> Angel: They're turning all these apartments into condos. Whoever bought this property [TWC] bought them.
>
> Monica: They're doing that just to drive Blacks further out. Shit. Jack it up where we can't afford it. That's why it's so hard to move.
>
> Kim: To me, it seems like its gentrification all over. [Ayana: Everywhere]. They're making it so high that you can't afford to live in the city. Everyone's going to start moving down south where it's cheaper to live. Or they're going to wind up being homeless.

The interjections by Monica, Ayana and Kim exemplified the frustration that all of the women noted about their homes and even TWC—the CBO where the discussion was taking place—being encroached upon. Many of the CRAs expressed that they wanted to move, but the soaring housing costs made the option to relocate almost impossible, adding yet another layer to housing barriers. The consistent use of the word "they" highlighted the racial and economic divide the women sensed relative to the White, wealthy contractors and residents driving the widespread incursion within their neighborhoods. Within Monica's neighborhood, the divide and inequality were so drastic that the new White-occupied residences across the street "look like one city" and her side of the street looked like a different city. Historically, the District was known as "Chocolate City" due to its predominantly Black population(Sturtevant, 2014). For the CRAs who were born and raised in the era of the "Chocolate City," the current transformation across the District left them feeling physically and economically forced out of their homes. The financial strain caused by gentrification not only limited CRAs' housing options, but left some CRAs fearing the potential of being homeless again.

Some of the women stated that Black homeowners, particularly Black females who were often the heads-of-household were also being taken advantage of during the gentrification process. Monica described how Black female

homeowners were the "rock" of their families, while wealthy White contractors were "taking" their homes away by coercing them to sell. Other CRAs corroborated that Black families were giving up homes that had been in their families for years, because of financial strain, or being forced out of housing complexes that would be turned into condos that current residents could not afford.

Image 6. Gentrification

Crime & Safety. Every CRA reported frequent violent crimes in their neighborhoods, some of which took place right outside their front doors. Women discussed various shootings, assaults, drug dealing, and drug use within their buildings and neighborhoods. Monica's and Kim's apartment buildings

were labeled neighborhood "deterrents," a term the CRAs used to classify areas or buildings targeted by the police for their high density of violent crimes. It was not uncommon for the CRAs to state that they stayed in their homes, avoided certain entrances to their buildings, or set up security cameras in their homes to feel safe. Kim described the experience as follows:

> For me it sucks because I feel like I'm in a prison. I really do. I feel like I'm in a prison. When my grandkids come over we can't let them go outside and play. We got a little playground, but they can't go out there because it's always the [drug] dealers—that don't even live in the neighborhood—right there and so we don't feel safe with them even going outside and enjoying the community.

Other CRAs echoed the feeling of being a "prisoner" in their own homes because of the bars, gates, and cameras that local law enforcement and property management installed to "protect" residents. Kim also described restrictive "loitering rules" at their housing complexes that kept her from even being able to sit in her car within her parking lot. The "bars" and constant "watching" made the women feel trapped rather than safe. Similar to the sentiments expressed in reference to gentrification, CRAs noted that they felt invaded and controlled by outsiders and housing management.

Exposure to alcohol and illicit drug use in their buildings and neighborhoods was another aspect of the social environment that CRAs described as being a constant stressor, particularly for some of the women that were in recovery. For instance, Monica stated:

> I live on a dope strip. I didn't want to take pictures of niggas slumped over with 211[alcohol] bottles in their hands sitting' on my block or the little girls [her neighbors] that come out at night — you know you can look at them and tell that they geekin' out [high].

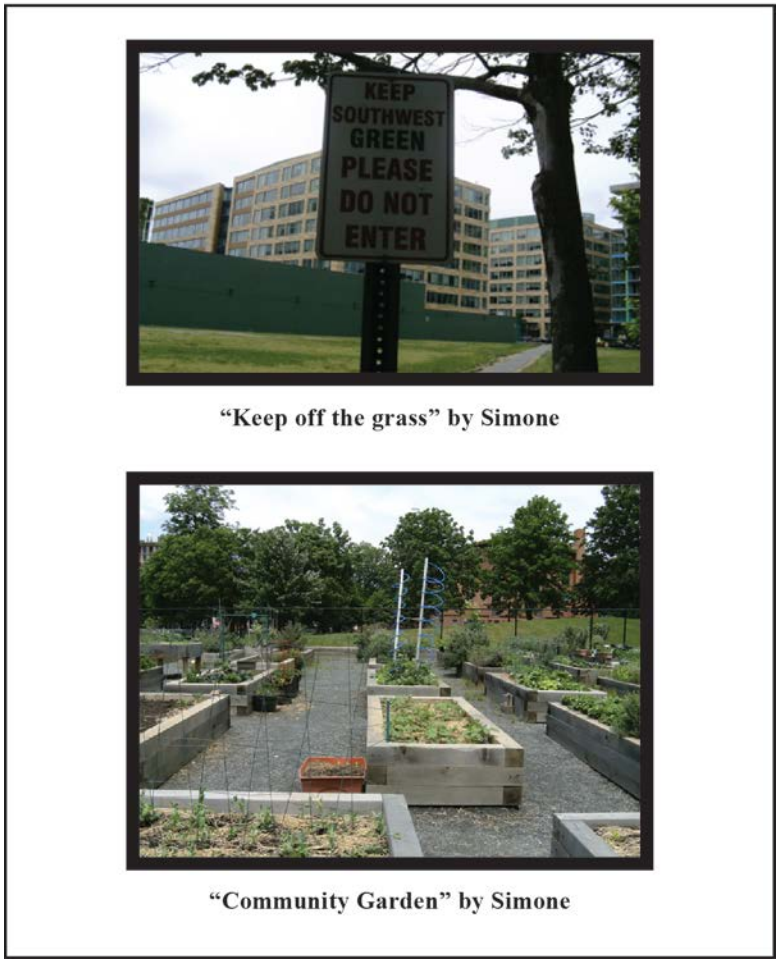
While some viewed drugs and addiction as phenomena that "comes with the territory" of living in the District's poorer neighborhoods, all of the CRAs felt that they had no other housing options at the time of the study (See Section 4.3.3). Mickey expressed this sentiment in her statement, "When I moved in, I didn't think about moving anywhere else because I wasn't gonna' have another place to move to." Again, this suggests that some of the women felt trapped or locked into their housing, and consequently the distressing impact of the social environment associated with the neighborhood. So while housing is meant to facilitate health, both physically and mentally, the social environment and lack of mobility experienced by the CRAs neighborhoods left them feeling imprisoned.

Conflict. Two of the CRAs discussed positive experiences with the gentrification of their neighborhood. Monica said that she appreciated the influx

of police presence that accompanied the new wealthy White residents in her neighborhood. Gentrification made Monica's neighborhood a "high priority," so police finally came to address some of the "crime" and "safety" issues that all of the CRAs felt characterized their neighborhoods. Simone noted that she appreciated the new community garden that was built in her neighborhood.

> This is the community garden where all pretty much can volunteer. So plant your own [seeds] but you have to take care of it. It's a community garden so we got Whites, Blacks, you know anytime they get together and you get a box that you can plant your own tomatoes, celery, or whatever.... But I never garden there.

While Simone saw the new community garden as an asset that came along with the gentrification of her neighborhood, she also did not access the garden or new parks being developed. The gentrification in Simone's neighborhood in the Southwest quadrant of the District was extremely rapid (Sturtevant, 2014). By the conclusion of this study, the brand new community garden was torn down to build condos.



"Keep off the grass" by Simone

"Community Garden" by Simone

Image 7. Gentrification

With regards to crime and safety, CRAs conveyed counter-narratives where their familiarity with the neighborhood and informal social ties gave a feeling of safety. The women of MTS had lived in their current neighborhoods for an average of nine years (See Table 2). Their lengthy experience in their respective neighborhoods made the CRAs feel "comfortable" or at ease. Candace lived in her neighborhood for the past 17 years — her children even went to the same grade schools she attended. Her familiarity with her

neighborhood gave her a sense of safety despite her perception of "crime rates rising." While a lot of violent crimes happened in her neighborhood, she did not feel that they "directly affected her" and she loved her neighborhood.

Some CRAs felt that they were respected by the men affiliated with the crime in their neighborhoods because they were older Black women. As previously mentioned, the CRAs described women as often being the head of the household in Black families. Within their communities, this respect for Black mothers translated into informal social ties between the CRAs and the younger generation of Black men in their neighborhoods. These informal social ties gave some of the CRAs a sense of security or safety, sometimes in the form of being given warnings before violent crimes would occur in their neighborhoods. Mickey explained, "When I first moved around here the guys started talking to me, annoying me and stuff and they would come outside and tell you when stuff was about to go down: 'Get your butt in the house.'" Mickey's experience illustrated some of the CRAs' complex relationships with the neighborhood guys, where the same individual causing a nuisance and threat to community safety also "looked out" for the older Black women in the neighborhood.

"Death's Doorstep" by Mickey

"That's my front door. Since I've been living there 6 to 8 people have gotten shot in front of my front door. But I love my neighborhood. I like the neighborhood because usually you get warned before stuff like that happens. If a shooting was going to kickoff of or someone on 22nd gonna' act stupid or something like that they'll come and tell us" (Mickey)

Image 8. Crime and Safety/ Informal Social Ties

Outside of police presence, green space, minor efforts by property management, and young men in the neighborhood looking out for the older Black women, the CRAs felt the social environment of their neighborhoods was depressing and a constant stress on them mentally. While crime, violence and substance use might "come with the territory" in poor neighborhoods, CRAs were forced to live in the same risky environments that they originally hoped to escape.

4.3.4 "Why women cry": Are women's HIV/AIDS housing service needs being met?

"Disparities in services" was another key theme in the women's experiences with housing. The CRAs very passionately described their perceptions of inequitable distribution of resources, particularly the allocation of HIV/AIDS funds and services for men that have sex with men (MSM) and transgender women compared to cisgender women. In the course of data collection, TWC was charged with raising awareness about PrEP[2] as part of a larger campaign by the DC DOH; a campaign that had previously focused on MSM and transgender women. This was one example the women mentioned as making them feel as though MSM and transgender women were being prioritized over them, despite a clear need amongst cisgender women. CRAs also expressed frustration that TWC was the only organization, amongst numerous HIV/AIDS organizations within the District, that was primarily focused on WLHA. While discussing the limited HIV/AIDS funds, particularly the dwindling allocations towards housing, the phrase "transgenders get everything" repeatedly came up. Kim elaborated on this point with the following response:

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[2] PrEP (Pre-Exposure Prophylaxis) is prevention medication for HIV-negative people who are especially vulnerable to getting HIV

> Ryan White (RWPC) is paying more money for transgenders. Not only transgenders, MSM community [too]. They paying more money for the MSM community and transgender community. What about the [cisgender] women?

During the group discussion, the CRAs grappled to understand the reasoning behind the perceived inequitable distribution of funds within the HIV/AIDS services in the District. Eris, who is a member of the RWPC, teared up while expressing the group's shared frustration about the lack of funding for HIV/AIDS services and housing for WLHA:

> Why don't you [government officials] see [that we need this funding]? You see the problems. You see the pain. You see the needs [of WLHA]. What is wrong? Why can't you figure it out and give [funding] where it should be given?

Eris' statement would suggest that District officials were well informed about the needs of WLHA, and that funding allocations did not reflect an adequate response to these needs. Yet, despite Eris' perception that the needs of WLHA were well known, the CRAs discussed how the DOH's means of community engagement and HIV/AIDS stigma stifled the voices of WLHA from being heard by District policy-makers. As a member of the DC HIV Prevention

Planning Group,[3] I am aware that, outside of provider feedback, the DOH relies on consumer surveys, focus groups, and RWPC town-hall meetings as their chief strategies for community engagement with PLHA. Strict federal and local funding deadlines often force the DOH to rely on convenience samples of different targeted subpopulations of PLWH for this data collection, however. This means that the DOH often relies on TWC, the only HIV/AIDS service organization in the District focused on the needs of WHLA, to connect with WLHA. Kim discussed her perception of this process of engagement in the following way:

> They [DOH] say the problem is the women won't come out to these [RWPC] town hall meetings and speak their piece. And if we came out more, like they say there's power in numbers…But when it comes down to the numbers of HIV and AIDS you have more MSM and transgender living with the virus. So they gone always have the more in numbers. But we just need more of us to show up.

[3] Group that guides HIV prevention in the District including determining populations in greatest need of prevention services

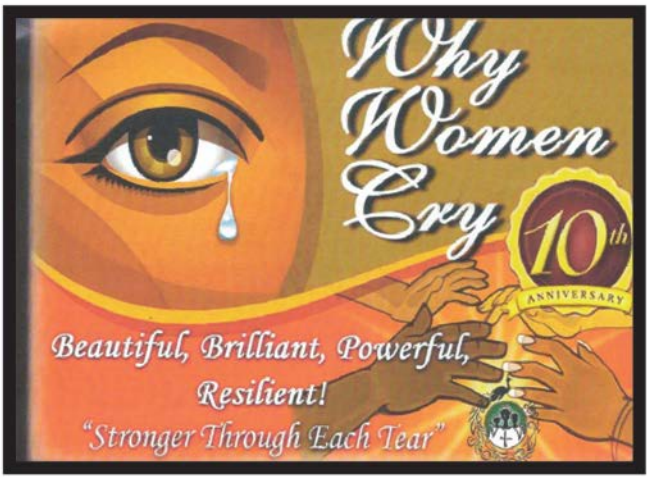
Kim's statement addresses not just WLHA's low attendance at RWPC town halls, but also the perception that MSM and transgender women outnumber WLHA amongst cases of PLHA. The DOH relies heavily on epidemiological data in determining funding allocations and deciding on the ranking of priority groups. Other CRAs agreed that between the epidemiological data and low attendance at community engagement activities, the voices of WLHA were often lost. Detailing why more WLHA do not attend engagement activities, Monica explained:

> A lot of women, even those that have dealt with this as long as most of us, are still caught up and not wanting nobody to know [their status] and there's the stigma. But if you worried about how are you going to make it better for every other woman that's living with this…, we are the only women's program that comes out and does anything [advocacy for WLHA].

As a group, CRAs shared the sentiment that TWC was the only program focusing on WLHA, and that this one organization was expected to carry the weight of being the voice for one of the key subpopulations of PLHA in the District. The CRAs also discussed feeling uncomfortable or unwelcomed at RWPC meetings, which they perceived as being largely attended by MSM and

transgender women. One CRA mentioned a male RWPC member commenting that cisgender women only came to RWPC town hall meetings to access food and subsequently leave.

With regards to stigma, over the course of this study CRAs mentioned various groups within TWC that sought to assist women with self-advocacy including becoming more comfortable with disclosing their HIV positive status. Nevertheless, four CRAs described their deep discomfort and inability disclosing their status with family and partners because of the fear of stigma. This process often involved many years between knowing their status and the time of disclosure. Eris explained that this stigma affected Black women particularly by saying. "Why women cry? We cry because of the stigma with HIV…Black women more than any other women in the US are getting HIV."



"Why women cry" by Eris

Image 9. Stigma

CRAs felt that epidemiological data often drove the unequal distribution of HIV/AIDS service funds to MSM and transgender populations. Still, they perceived that policymakers viewed the housing and HIV/AIDS service needs of WLHA as secondary. Stigma and having only one organization representing WLHA stifled their voices and needs from being heard through the DOH's current vehicles of community engagement.

4.4 Other Findings

Photovoice methods have often been associated with the enhancement of participants' empowerment, and as a way to disseminate images and take action

to inform health policy(C. C. Wang, 1999). However, another key component of the use of photovoice methods in the current study was the direct benefit that some CRAs received as part of their involvement. As a community researcher working with a marginalized population, it was important to me that the outcomes of my dissertation not only serve my academic requirements and add to the research literature, but also provide value to the participants beyond just monetary compensation. More than a Shelter did directly benefit the women by empowering them via their study participation and photos to: demand that property management repair their hazardous living conditions (e.g., remove mold, holes, and building doors missing locks); request that housing services help them with relocation; and seek counsel from lawyers if necessary. Mickey was one of the three CRAs who notified property management of her participation in the project, and that she planned to photograph the hazardous exposure to mold and decrepit structures in her unit:

> I said, "Look, I'm taking a picture of everything in this apartment. Y'all better get it together before I send it in [to Housing Authority Office]". Honey, within a week or so they came and fixed that. I got that shit done! I said I'm taking a picture of this because I'm on a project. And when I told them that, they immediately came to my house and fix my

stuff—immediately! This is the best project that you've ever had because I'm getting something done in my house. I felt good about doing that.

For Mickey, the struggle with management to address the mold in her bathroom had lasted for years, and within three weeks of having her camera to document the conditions of her unit, management finally fulfilled her maintenance request. Monica and Brandy shared similar experiences with threatening management with documentation of the slum-like conditions of their units. For Brandy, who had one of the more extreme cases of mold exposure that forced her out of her home, her participation in this study provided her with evidence to be used by a lawyer to lobby for a housing transfer that she was fighting for. Brandy said that she planned to go "straight to a lawyer" with her photos and hospitalization papers following her participation in the study, because her previous efforts to work with housing services to be relocated to a safer sanitary unit had been unfruitful.

"Before and After" by Mickey

"I said 'look I'm taking a picture of everything in this apartment. Y'all better get it together before I send it in'. Honey, within a week or so they came and fixed that. I got that shit done! I said I'm taking a picture of this because I'm on a project. And when I told them that, they immediately came to my house and fix my stuff—immediately! This is the best project that you've ever had because I'm getting something done in my house. I felt good about doing that." (Mickey)

Image 10. Empowerment

Besides advocating for housing improvements, some CRAs revealed that they were interested in the MTS project because they wanted to show "how [their] community needs improvement," and "how unsafe it is to live" under some conditions and within some neighborhoods. For a group marginalized at multiple intersecting social locations (e.g., race, gender, class, and HIV status) and whose housing service needs and grievances had been ignored or overlooked by those in power, the More than a Shelter Project provided an

alternative platform to share their experiences, reflect about them, and develop critical consciousness during group photo discussions.

CHAPTER V: DISCUSSION

5.1 Summary of Findings

As part of this dissertation, I explored WLHA's experiences with HIV/AIDS housing services in Washington, DC and found that the women who participated in the study mainly discussed four key aspects derived from their experiences. First, the women were not familiar with the HOPWA program, and noted that housing services for WLHA were very limited outside of the options involving access to shelters and transitional housing. Navigating through these was an arduous process, and women experienced many barriers related to lack of affordable units, access to and reliance on the Housing Choice Voucher Program, and discriminatory practices related to class, gender, marital status, and sometimes race. The women discussed the hazardous physical conditions and vulnerability linked to the social environment of their homes and neighborhoods, and the combined negative impact these factors had on their physical, mental and emotional health, as well as on their families. The fourth aspect noted by this study's participants was the perception of an inequitable distribution of funds among the various likely beneficiary subgroups. Specifically, this study's participants stated that MSM and transgender women were more of a priority in the District's HIV/AIDS funding allocations and services, and that the voices and needs of WLHA were stifled by both stigma and

the District's imperfect means of promoting genuine community engagement with WLHA. One unanticipated finding derived from this study was the importance of community researchers' actions fostering a direct benefit for participants when working with marginalized populations; benefits that surpass the basic incentive model.

5.2 Conclusions in Relation to Current Research

The results of this study align in some ways with findings in the existing literature. Namely, some of the women did see a positive impact on their health: the housing provided gave them a place where they could take their medicines; it provided social support via a place where to take care of their families and have family gatherings; and gave them a sense of pride in where they lived, which has been found to lead to good mental health through the mechanism of reduced stress (A.A. Aidala et al., 2007; A. Aidala et al., 2005; Cederbaum et al., 2013; L. A. Smith & Pynoos, 2002). A qualitative study also found that the way in which housing influenced mental health did not change by ethnicity, gender, or geographic location (L. A. Smith & Pynoos, 2002). While my study did not compare individuals of different ethnicities or gender, the women in this study observed that their unique intersectional identities lead to certain outcomes regarding the housing options available to them (Acevedo-Garcia, Werbel, Meara, Cutler, & Berkman, 2004) , informal social ties with young black men in

their neighborhoods that led them to feel safer in an otherwise dangerous environment (A. A. Aidala & Sumartojo, 2007), and sensing that they are prioritized behind MSM and transgender women by the DOH.

However, the findings of this study depart from the existing literature in important ways. Whereas in the qualitative literature negative impacts of housing services were briefly mentioned but mainly outshined by the positive effect housing can have on health (L. A. Smith & Pynoos, 2002), this research found that the negative influences of housing on mental and physical health – because of both hazardous physical living conditions and stressful social conditions – were front and center. This aligns with urban health theory, that both the built environment and social environment involving gentrification and associated economic and racial segregation can have an impact on health (Galea & Vlahov, 2005). Qualitative research findings suggest that participants may be hesitant to discuss negative aspects of their communities with outsiders in fear of further stigmatizing their neighborhood, racial group, or themselves (B. A. Israel et al., 2006), as was exhibited when the CRAs discussed their reluctance to take pictures of some of the hazardous conditions in their homes or stressors in their neighborhoods.

My concerted effort to build rapport with both the TWC staff and clients prior to the research study facilitated the CRAs willingness to share and

photograph some of the stressors they identified within their housing. Part of the rapport building included reinforcing the community-based participatory research (CBPR) principle that the researcher and community members are working together to discover a better understanding of a key issue for the community members, which for this study focused on the broader impact of experiences with housing assistance and daily living for the CRAs.

The CRAs expressed conflicting experiences in relation to their housing, where they were physically and mentally stressed by their built and social environment, but still loved their housing and neighborhoods in spite of it all. This is in part due to the lack of affordable housing in DC. Research findings have documented that Black residents tend to have lower perceptions of stress related to the social environment (e.g. concentrated poverty, economic and racial segregation) in comparison to white residents in the same urban neighborhoods because of their social ties to the neighborhood (Schulz et al., 2008). The lack of other housing options and overall lack of mobility that the women experienced supported WLHA to want to stay in the same neighborhood, rather than move elsewhere, and further reinforced the development of the women's neighborhood ties (Acevedo-Garcia et al., 2004; Schulz et al., 2008).

The District's pooling of different funding sources to provide for PLHA may be attributable to the fact that the women were not familiar with the

HOPWA program, a similar finding noted in a study in Chicago, a city that uses a similar decentralization system to address the needs of low-income individuals in need of housing (Scott, Ellen, Clum, & Leonard, 2007). However, the CRAs inability to advocate for their basic human right to adequate housing (United Nations, 2014) speaks to a larger social-structural problem related, in part, to how housing codes are enforced and tenants' housing rights knowledge. HOPWA, Section 8 housing, and the District as a whole have developed standards for sanitary, safe, and stable housing that landlords are obligated to meet (Department of Consumer Regulatory Affairs, 2010; Department of Housing and Urban Development, 2007). However, the women participants did not feel they had to power to advocate for these rights to be met, particularly when property managers were unresponsive to basic maintenance requests. As residents within the District, the CRAs have the right to report violations of housing codes to the Department of Consumer Regulatory Affairs (Department of Consumer Regulatory Affairs, 2010), however, due to their social position as low-income Black women, the CRAs believed their power and resources limited their ability to advocate for the enforcement of these housing codes.

5.3 Study Limitations

My study was subject to several limitations. While I aimed to explore the impact of HOPWA on the lives of WLHA in Washington, DC, it became

immediately evident that this funding mechanism was not well known or understood by participants. The DOH combines funding mechanisms to address homelessness and housing instability in the city as a whole, and PLHA is a key population in those efforts. The experiences of the women who participated in this study may be related to housing services in the District, and not just those accessed through HIV/AIDS service organizations. Although I was able to verify that all of the CRAs received some form of housing services from a HOPWA-funded program and organization, the women discussed current and past experiences in their journey to securing stable housing accessed from non-HIV/AIDS focused programs. Nonetheless, the CRA's experiences speak to how the District addresses housing instability for WLHA and, in turn, the systemic impact posed on an already vulnerable and stigmatized population.

Second, I used a convenience sample of WLHA, all of whom were long-term clients of TWC, a very unique organization and perhaps the only organization in the District that focuses on the needs of WLHA (The Women's Collective, 2012). As part of its mission, TWC encourages their clients to participate in group activities that promote self-empowerment, advocating policy change, and self-advocacy for WLHA. Consequently, the CRAs in this study were clearly empowered and willing to self-advocate. Their experiences may differ from WLHA that may be disaffected and not connected to a support

system, or who are unfamiliar with the District's policies on HIV/AIDS funding allocations and community engagement mechanisms.

Also related to this study's sample, all but one of the CRAs were stably housed for more than year at the time of data collection. The women acknowledged that securing stable housing seemed even harder now, than in the past. Women currently trying to navigate housing services may have different experiences than this study's CRAs. Also, all of the CRAs were older Black women, who described the prevalence of social-structural challenges related to their age, gender, marital status, and race in their experiences with their accessing housing services. The recent changes in leadership at the federal level and a re-tooling of the Ryan White Program in the District (Bowser, 2016) could potentially change funding allocations and housing services for PLHA in the future.

5.4 Implications for Public Health

With scientific evolution, HIV/AIDS is no longer a death sentence, and public health prevention and intervention programs now appear to have an even greater biomedical focus. Whether it's using PrEP for prevention or ART for treatment, linking PLHA into medical treatment services and viral load suppression are key objectives of many public health strategies (Bowser, 2016). Housing is used as a primary intervention to link PLHA to these treatments,

primary care, and other services. In this effort to concentrate on treatment, public health has lost its focus on the essential and everyday living experiences and quality of life of PLHA. The absurd waiting times, hazardous physical and social environments, and discriminatory policies built in within power hierarchies that the women in this study experienced while navigating housing services was nothing short of structural violence.

As public health professionals we preach "housing equals health" and argue that housing is a fundamental human right (United Nations, 2014). However, the District's current housing service strategies appear to focus on the four walls and a roof of housing, and have stripped away the primacy that *quality* of housing has on health. While having a place to live may indirectly improve mental health and physical health through supporting health promoting behaviors and linkage to services, housing in and of itself doesn't directly improve physical health. Moreover, exposure to mold, pests, violence, and numerous other physical and social hazards do have a direct and negative impact on both physical and mental health (A. A. Aidala & Sumartojo, 2007). The *quality* of the housing, both physical and social, did have a direct impact on the health of the CRAs in this study, as well as on their families. Housing is a fundamental human right (United Nations, 2014) and hazardous or sub-standard housing conditions should not be acceptable, especially in instances where the

population being served is both marginalized including PLHA. We cannot just advocate for affordable housing, it needs to be affordable housing that will not compromise the health of WLHA.

If we shift the public health focus back to health and not just the bare minimum housing comprised of four walls and a roof, we can promote housing service programs and interventions that are fully responsive to the everyday lives and intersectionality dimensions evident in the lives of WLHA. For populations such as WLHA, who experience an absence of social and economic power, we must advocate for housing services that help marginalized populations thrive and not just survive in conditions that compromise their already vulnerable health status.

5.5 Implications for Policy

Housing, and, more specifically, affordable housing, is a problem in the District that goes beyond the women of this study or even WLHA in general. However, this study does make an important contribution by shedding light on how WLHA in the District experience their daily struggle advocating for their housing needs. The women in this study did not feel like their voices are being heard. The DOH supports various community engagement activities as part of their periodic needs assessments preceding priority ranking of consumer priorities and funding allocations; however, the CRAs did not feel the ways in

which the DOH engages WLHA were effective or sufficiently inclusive. For example, the DOH uses consumer surveys implemented by health care providers/CBOs, focus groups targeting key populations, and RWPC town hall meetings to connect with PLHA. From anecdotal experience, consumer surveys and focus groups use convenience samples and operate on tight deadlines in order for findings to be applied to the District's annual priority ranking of consumer needs preceding funding allocations. Many times the Women's Collective is identified and engaged as the representative voice for all women of color affected by HIV/AIDS in the District (The Women's Collective, 2012). The women linked to the Women's Collective are purposively sampled for these surveys and discussions. However, after talking to the women in this study, many WLHA don't attend RWPC town halls, particularly WLHA not affiliated with TWC, because they feel unwelcomed or stigmatized given their HIV/AIDS status and race. All told, they are the disaffected populations that must be engaged.

The women's feedback collected relative to their views regarding the District's methods for promoting community engagement is one significant contribution of this study. The CRAs described the voices of WLHA being stifled by only having one HIV/AIDS organization that focuses on all women, and the role that stigma plays in deterring women, particularly disaffected women of

color, from attending engagement events including RWPC town halls. The DOH needs to do more research or inquiry as to why WLHA do not feel welcome at RWPC town halls. As a key platform for PLHA and advocates to have their voices and concerns heard, it is critical that WLHA are seated at the table for these discussions. Issues relative to stigma were a major concern for the women, particularly because of their intersectional identities as low-income, Black WLHA. While the DOH makes efforts to gain the insight of consumers, providers, and advocates to assess the needs of different populations among PLHA in the District, resources may need to be invested; for example, reliance on different vehicles and venues for ensuring inclusive outreach and genuine engagement to identify and meet the needs of particular populations, including WLHA. The TWC cannot be the sole voice of WLHA in the District, and policymakers, researchers, and community members need to join efforts and collaborate to determine how best to access these communities, particularly women who are disaffect and not linked to a support service such as TWC. Collaborations with local universities and researchers can help provide resources, including teams comprised of collaborators across different disciplines as well as community-based researchers with expertise and a commitment to serving the disenfranchised. These efforts can help foster community partnerships designed to undertake needs assessments, which may include using

specific outreach or engagement strategies tailored to particularly vulnerable populations.

Department of Health officials should also consider using additional methods and approaches including photovoice as an engagement tool to more fully understand what goes on in people's lives, particularly in relation to housing. Programs such as HOPWA have specific standards of habitability that their permanent housing units must meet in order to ensure that beneficiaries are placed in safe and sanitary living conditions. However, the majority of WLHA in the District are not living in HOPWA-funded permanent housing (Bowser, 2016; Department of Housing and Urban Development, 2017), as documented in this study. Alternative housing assistance programs including the Housing Choice Voucher program rely on privately owned properties subsumed under the DC housing code standards (Department of Consumer Regulatory Affairs, 2010). Under this regulation the mold, insects, mice, holes, and building doors without locks that the CRAs photographed as part of this study, would all be in direct violation of the DC Housing Code. However the burden falls on the tenant to report any of these violations to the DC Department of Consumer and Regulatory Affairs in order to have an inspection, followed by assistance needed when resolving issues with landlords (Department of Consumer Regulatory Affairs, 2010). While affordable housing is limited, HOPWA provided housing

information to more than 10,000 PLHA in 2016 (Department of Housing and Urban Development, 2017). Using this HOPWA service to provide PLHA information on housing codes, tenant rights and support when submitting claims, may help to empower residents like the CRAs who participated in this study when seeking to resolve housing issues, and combatting social-structural hierarchies that reinforce the powerlessness reflected in the "what can I do" feeling the women experienced.

5.6 Implications for Future Research

Future research should use photovoice methods to explore the experiences with housing across different key populations in the District besides WLHA. The CRAs observed that the needs of MSM and transgender women appeared to be more of a priority in the context of the District's priority subpopulations. Future research should explore the experiences of MSM and transgender women in the District seeking housing services, as well as assess the scope of their representation within HIV/AIDS organizations, services and funding allocations. Also, the women in this study were older females with a long history of being linked to support services and housing assistance. Their discussion of changes in the current District's housing climate, and rapidly changing social environment of neighborhoods lends credence to the fact that future research should assess whether regardless of population characteristics and identities, there are more

commonalities than differences among them. For example, it would be important to know how the needs of younger women with dependents are being addressed and met, to more fully understand where these groups' experiences share similarities, and where these may differ.

Also, researchers should partner with the DOH to explore the experiences with housing services from the perspective of providers (i.e., case managers, landlords, and housing staff) to assess how/if housing standards are regulated and enforced under the housing codes of HOPWA permanent housing units and the Districts housing code. This may help develop potential solutions to housing standards from the perspective of officials with the power and responsibility of their respective institutions.

5.7 Recommendations

In my evolution as a student researcher using photovoice methods as part of my dissertation, I found it important to acknowledge my capacity to contribute to improving the current hardships the women I was working with were facing. Photovoice methods are rooted in empowerment and advocacy. As a student researcher you must have an extra awareness that while you have a commitment to the academic process, you have the capacity to transform a fundamental need that is rooted in the inextricable link between health and human rights. Providing the women with $11 cameras and printing

photographs of the housing code violations that they took within their units and buildings had a direct benefit to some of the participants.

In order to honor my responsibility as an advocate and a researcher, outside of the academic requirement, it is still within my responsibility as a witness of this project to facilitate the CRAs in taking one step closer to policymakers and the HIV/AIDS community to enhance their lives and wellbeing. The use of photovoice data collection methods with interpretive phenomenology allowed me to complete an enriched exploration of the experiences of WLHA with housing services. Using photovoice methods not only aided in unveiling findings that can influence policy and empower the study's participants, but it also gave a voice to a marginalized group in order to bring about change in their immediate housing situation. This direct benefit to the participants was a critical component of the study. As researchers, we have the capacity to contribute to positive change, to advocate, and promote the formulation of policymaking that can impact the health and wellbeing of those who are most vulnerable and stigmatized.

5.8 Conclusion

The findings derived from this study suggest that housing services needs not only focus on providing stable housing, but also helping residents advocate for the right to sanitary, safe housing, including WLHA who experience a

complex web of social-structural factors that influence their housing experience. Housing is a primary health promotion measure, with the potential to lead to positive physical and mental health outcomes, but only if our methods enforce adequate housing in relation to the built environment, the surrounding social environment, as well as the mechanisms in place to ensure adequate and timely access and well-conceived regulatory mechanisms. Affordable housing is a very challenging obstacle in the District of Columbia. However, we cannot continue to waste our limited resources to support a housing service model that reinforces long waiting times, providing "housing information" to many yet they have no knowledge of extant programs, housing only a few, and minimal enforcement of housing codes intended to ensure quality of life and safety for the few consumers ultimately placed.

The current Mayor's most recent campaign strategies to end the HIV epidemic in the District (Bowser, 2016), strongly advocates for the importance of housing and redesigning the HOPWA program to help beneficiaries achieve self-sufficiency by aiding beneficiaries with employment assistance and financial services. Self-sufficiency is a critical step to encourage people to phase out of HOPWA services so that the program can use its limited resources to aid more newly identified PLHA while discouraging long waiting times for those seeking housing assistance. However, the findings from this study also suggest that the

District's HIV/AIDS strategies should also evaluate their engagement tools when conducting housing needs assessments with WLHA, especially those subgroups that because of their intersectional dimensions are likely to be disaffected.

Housing can improve health, but only if the housing units are habitable. Placing people with vulnerable health conditions in hazardous living conditions is a waste of resources. For housing to improve health, you need more than just four walls and a roof. Going forward, it's important for public health and HIV/AIDS advocates to focus not just on housing, but also on health and quality of life, empowering WLHA to advocate for the enforcement of housing codes, and effective engagement approaches with WLHA to ensure their voices and needs are being heard, understood, and responded to.

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APPENDIX A: Individual Interview Guide

INDIVIDUAL INTERVIEW GUIDE

INTRODUCTION

I'd like to begin by thanking you for coming in to meet with me today.

The purpose of this discussion is to give you a chance to share your photos, thoughts and opinions about your experience living in HOPWA-funded housing. We also want to know about how the HOPWA program may have affected you. There's so little research on these topics and so we're really interested in what you have to share. I have uploaded your photos and I would like you to take a few minutes to go through and select 5 or 6 photographs that you would like to discuss with me today. Once you've selected your photos I will ask you a few questions about each photo and just give you a chance to discuss them. Do you have any questions before we begin?

TURN ON DIGITAL RECORDER

Photo Discussion Questions

1. What made you choose this particular photograph?
2. What was going through your mind when you took this photograph?
3. Tell me how your photograph relates to your experience with the HOPWA program?
4. What caption would you give this photo? Why?
5. Were there any photos that you didn't take? Why?

CLOSING COMMENTS

Well that's it. We're done. I know that was a long discussion. I want to thank you for your patience and taking the time to give such detailed information and for sharing your experiences. There's so little research on the impact of the HOPWA program on the lives of women and what you have shared will be great for bringing awareness. Before we close do you have any more comments or questions about any of the things that we talked about today?

Again, thank you and I look forward to having you share your photos and experiences with the other community researchers during the group photo discussion.

APPENDIX B: Group Discussion Guide

GROUP PHOTO DISCUSSION GUIDE

INTRODUCTION

I'd like to begin by thanking you for coming to this photo discussion group. I hope everyone has helped themselves to refreshments. My name is (FIRST NAME ONLY). I'm here to guide the discussion, to listen to your opinions and ideas and to encourage everyone to participate. Why don't we go around and introduce ourselves, using just our first names, and say where we're from or grew up. I'm originally from (PLACE).

The purpose of this discussion group is to share your photos, thoughts and opinions about your experience living in HOPWA-funded housing. We also want to know about the impact of the HOPWA program impacts your life. There's so little research on these topics and so we're really interested in what you have to share. There are no right or wrong answers, just different opinions and experiences, and I want to encourage you to talk to each other, not just to me. To make this discussion interesting and comfortable for everyone let's come up with some agreements for the discussion:

- Please only one person talk at a time,
- Speak loud enough so other people can hear,
- Turn off cell phones and pagers
- Feel free to visit the restroom any time without asking. The bathrooms are …
- Please don't share the names or what anyone in the group has said with anyone outside the group

Is everyone okay with that? Does anyone have any questions?

TURN ON DIGITAL RECORDER

WARM UP QUESTION

So who would like to share their photos first?

[Note to facilitator: Ask participants to volunteer to present photos and develop a presentation order prior to beginning photo discussion so that you can prep the photos in order of presentation without unnecessary disruption during the discussion]

Photo Discussion Questions (For Presenting Photographer)

6. What does this photo show?

7. What do you want to say about it?

8. How has the HOPWA program impacted you

9. What caption would you give this photo?

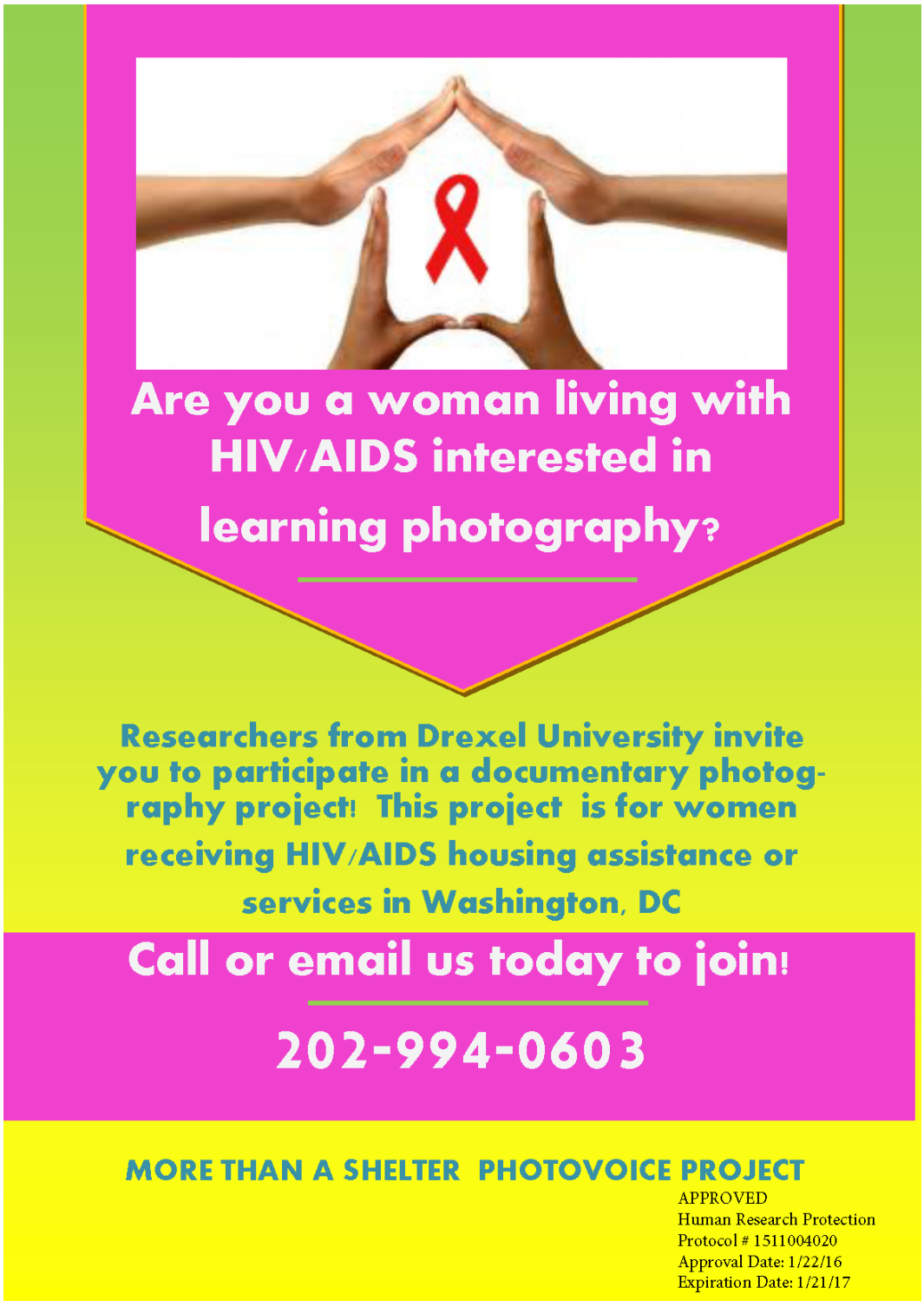
CLOSING QUESTIONS (for the entire group)

Okay, so we're done with the photo presentations. Do you have any more comments about any of the things that we talked about in this group today?

Are there questions that we didn't ask you about your experiences in HOPWA-funded housing that we didn't ask you but should have?

Thank you very much for your participation. Your photos, thoughts and opinions on these topics were very insightful.

APPENDIX C: Recruitment Flyer



MORE THAN A SHELTER

Is a VOLUNTARY and CONFIDENTIAL Photovoice project being conducted as part of a research study designed to support women living with HIV/ AIDS experiencing housing challenges

WHAT DO I HAVE TO DO?

- Take photos of your life and experiences with HIV/AIDS housing for a month
- Share your photos & experiences with researchers and other women in the project during group discussions

WHAT DO I GET?

- Free camera to document your life
- Free training form a professional photographer
- Compensation up to $60 for your participation

WHO CAN PARTICIPATE?

- Women age 18 and older
- Currently receiving HIV/AIDS housing assistance or services in DC
- Speak English as your primary language
- Willing to take, discuss & share photographs of your experiences

Contact us to learn more about the project at:

Phone: 202-9954-0603

Email: jsm58@drexel.edu

APPROVED
Human Research Protection
Protocol # 1511004020
Approval Date: 1/22/16
Expiration Date: 1/21/17

APPENDIX D: Screening Tool

Date:_____

Where Recruited:_____ **Eligibility** *(Circle One):* **Eligible Ineligible**

SCREENING TOOL

Script: *"Hi, I'm with the More Than a Shelter Project. It is a photovoice study for women living with HIV/AIDS in Philadelphia experiencing housing instability. If you are interested in participating in the study I just need to ask you a few questions to make sure you are eligible. The information you provide on this form will not be shared with anyone outside the research study. You are free not to answer any question, but if you do not answer the question, we will not be able to find out if you meet all the criteria to participate in the research study. Are you interested in seeing if you 're eligible for the study?*

If yes, continue on:
.

1) How old are you? _____ (ineligible unless age 18 or older)

   The next few questions are a bit personal. You do not have to answer them, but if you do not, I cannot determine if you are eligible for this project. Your answers will be kept completely confidential and no one will have access to the information you share with me today.

2) Do you identify as a biologically born female?
   a. Yes
   b. No (if neither, ineligible)

3) Are you currently receiving HOPWA services in the city of Philadelphia? This may include housing, subsidies for bills, or other services?
   a. Yes
   b. No or on waiting list for subsidies/services (ineligible)

4) [If yes to question 3] How long have you been receiving HOPWA services in DC ?

   _____ (ineligible if less than 30 days today's date)

If the interviewer suspects cognitive impairment, please use the attached Folstein cognitive screening tool to determine eligibility.

If ineligible for any reason, Read SCRIPT ONE:

SCRIPT ONE: *I am sorry but you are not eligible to be in this study. Thank you for your time.*

If eligible, Read SCRIPT TWO:

SCRIPT TWO: *Great! You are eligible for the study. First I want to tell you more about the project. Then, I am going to schedule you for the first meeting where you will get your camera and trained on how to use it. During that first meeting we will also give you a consent form and enroll you in the study.*

APPROVED
Human Research Protection
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Approval Date: 1/22/16
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APPENDIX E: Demographic Survey

MORE THAN A SHELTER : DEMOGRAPHIC SURVEY

This questionnaire includes basic questions about you. To protect your privacy, please do not put your name or any other identifying information anywhere on this survey. When you are finished, please give the competed survey to the person who gave it to you.

Part 1: These questions ask for basic information about you. This information is so that we can describe the people who participated in this study as a whole. None of this will be linked back to you. Please write in your answers or circle the response that best represents your answer.

1. What is your date of birth? ____/____/____
   MM DD YEAR

2. How old are you? _____

3. What is your race/ethnicity? (Check all that apply)

   ☐1 Asian

   ☐2 Black, African American

   ☐3 Latino

   ☐4 White

   ☐5 Other (please specify)

_____

4. What is your relationship status?

   ☐1 Single

   ☐2 Married

   ☐3 Living with partner

   ☐4 Separated

   ☐5 Divorced

☐6 Widowed

☐7 Other

5. Do you have children?

☐1 No.

☐2 Yes

6. How many children do you have? _____
7. What are the age(s) of your children?
(Please list)_____
8. Do your children live with you?

☐1 No.

☐2 Yes

8. Do you think of yourself as……?

☐1 Heterosexual/Straight

☐2 Bisexual

☐3 Lesbian/ Gay/ Same Gender Loving

☐4 Something Else? Specify: _____

9. What is the highest level of schooling you have completed……?

☐1 Did not finish high school

☐2 Finished high school or GED

☐3 Some junior college or vocational school

☐4 Associates degree

☐5 Some undergraduate school

☐6 Bachelors degree

☐7 Some graduate work

☐8 Graduate degree

10. Are you currently employed full-time?

☐1 YES.

☐2 No

11. If you are not employed full-time, how long has it been since you were last employed?

☐1 Less than 3 months

☐2 3 to 6 months

☐3 7 to 12 months

☐4 More than a year

☐5 Not applicable: I am employed

12. If you are employed full-time, how long have you had this job?

☐1 Less than 3 months

☐2 3 to 6 months

☐3 7 to 12 months

☐4 More than a year

☐5 Not employed

13. If you are employed, about how many hours a week do you work? _____

14. How much money did you make last year before taxes? This might be difficult to calculate, so please make your best guess.

☐1 $0 - $4,999

☐2 $5000 - $9,999

☐3 $10,000 - $14,999

☐4 $15,000 - $19,999

☐5 $20,000 - $24,999

☐6 $25,000 - $29,999

☐7 $30,000 - $34,999

☐8 $35,000 - $39,999

☐9 $40,000 - $44,999

☐10 $45,000 - $49,999

☐11 $50,000 - $54,999

☐12 $55,000 - $59,999

☐13 $60,000 - $64,999

☐14 $65,000 - $69,999

☐15 $70,000 - $74,000

☐16 $75,000 or more

15. What are your source(s) of income (Please check all that apply)

☐ Earned Income

☐ Unemployment Insurance

☐ Supplemental Security Income (SSI)

☐ Social Security disability Income (SSDI)

☐ Veteran's Disability Payment

☐ General Assistance

☐ Temporary Assistance for Needy Families (TANF)

☐ Veteran's Pension

☐ Pension from Former Job

☐ Child Support

☐ Alimony or Other Spousal Support

☐ Retirement Income from Social Security

☐ Private Disability Insurance

☐ Worker's Compensation

☐ Other Source (Please specify)_____

16. Have you ever been incarcerated?

☐1 No.

☐2 Yes.

17. How many times have you been incarcerated?

____ ____ Times

18. What is the total amount of time that you were incarcerated?

____ Years
____ Months
____ Days

19. How old were you when you were first incarcerated?

____ ____ Years Old

20. Are you currently on parole?

☐1 Yes

☐2 No

Part 2: These next questions ask housing information. This information is so that we can understand our participants' current housing status and the assistance and services you may be receiving through the HOPWA program.

21. What is your zip code?_____

22. What neighborhood do you currently live in?_____

23. How long have you lived in your current neighborhood? _____

24. During the *last six months*, how many different places did you live? _____

25. Where are you living now?

☐ A house or apartment you paid for

☐ A house or apartment someone else paid for

☐ A motel, hotel, or boarding house

☐ A car, on the street, or in a homeless shelter

☐ A halfway house or other transitional house

☐ A drug treatment facility or housing

☐ Somewhere else?

26. How long have you lived there?

☐$_1$ Less than 3 months

☐$_2$ 3 to 6 months

☐$_3$ 7 to 12 months

☐$_4$ More than a year

27. What form of housing assistance do you currently receive through the HOPWA Program?

(Please check all that apply)

☐ Tenant-Based Rental Assistance (TBRA)

☐ Short-term Rent, Mortgage and Utility Payments (STRMU)

☐ Single Room Occupancy (SRO) Dwelling

☐ Community Residence Housing

☐ Short-term/transitional housing

☐ Project-based unit housing

☐ Master leased unit housing

☐ Scattered site unit housing

☐ Permanent housing

☐ Stewardship Housing Unit

☐ Supportive services/housing placement assistance

☐ Other form of housing assistance

(Please specify)_____

28. What form of supportive services have you received through the HOPWA Program

(Please check all that apply)

☐ Adult day care and personal assistance

☐ Alcohol and drug abuse services

☐ Case management/client advocacy/access to benefits & services

☐ Child care and other child services

☐ Education

☐ Employment assistance and training

☐ Health/medical/intensive care services

☐ Legal services

☐ Life skills management (outside of case management)

☐ Meals/nutritional services

☐ Mental Health Services

☐ Outreach

☐ Transportation

☐ Other activities/services

(Please specify)_____

☐ I have not received supportive services through the HOPWA Program

29. How long have you been receiving housing assistance through the HOPWA Program?

____ Years
____ Months
____ Days

You have now reached the end of the survey. Thank you again for your participation.

APPENDIX F: Photovoice Training Tools

PhotoVoice Ethics: Safety and Respect

With PhotoVoice, we are visual researchers as we take pictures of our lives as women living with HIV/AIDS and housing in the DMV and talk about this with others, you must keep certain guidelines in mind:

Stay safe! Make sure you are "SAFE" when you take the picture. For example:

Stand on a solid surface.
Look before you step into or cross a street.
Be aware of things around you, like traffic.

Ask permission. Always ask permission before taking people's photos for this project. Ask them to sign a photo consent form.

If people can be recognized in a photo, ask permission before showing their picture outside your group.

Be respectful. If certain people don't want their photo taken, respect their feelings.

Be prepared. Be ready to explain about the project to family, friends, or strangers, if they ask what you are doing.

A simple explanation is: "I am part of a PhotoVoice project investigating what it is like to be a woman and housing in the DMV. We are taking photographs of our lives and talking about them with other people in our group. Thank you for letting me take your picture."

When permission is not necessary. In a public place like a park, you can take someone's photo without permission, especially if they are far away and can't be recognized in the picture.

Respect the lives and safety of others. When you take photos for your project, think of people's safety first, and be respectful of their lives. For example:

If your friend is diabetic and the doctor told them not to eat sweets, avoid taking a picture of them eating cake.

If your friend doesn't have a driver's license, avoid taking a picture of them driving a car down the street.

Spirit of PhotoVoice Tip Sheet

Questions to think about when taking photos:

- What is it like to be a women living with HIV/AIDS (WLHA) without stable housing?
- What about my community and housing situation has helped me with my health?
- What about my community and housing situation has slowed down my health?
- What do I want to tell other people about women living with HIV/AIDS and housing?
- How is my life and housing different now from how it was before? What is better? What is worse?
- What are my hopes for the future? And what might help me get there?

Photo-Taking Tips:

- Tips for taking good photographs
  - Try different angles
  - Try different points of view
  - Keep the sun to your back, or to the side
- Tips for avoiding common mistakes
  - Keep your finger away from the lens
  - Don't cover the flash
  - To prevent blurry pictures, hold your elbows close to your sides, and hold your breath when you press the shutter (button)
- Camera not getting the job done? Feel free to use your camera phone!

Carry a notebook!

Write down ideas of pictures you want to take and why you took a particular photo

Ask permission to take someone's photo…

Always ask permission before you take someone's picture! If they say no, explain briefly what you are doing and why you want to take their picture. Your explanation can simply be: "I'm working on a photography project for women and housing issues in the DMV, would you mind being in one of the photos?" If they still say no, take a picture of something or someone else instead

Photo quality is not important!

PhotoVoice is not about the quality of your photographs. It is about taking pictures that mean something to you as woman living with HIV/AIDS in the DMV.

APPENDIX G: Camera Training Tools

Photography 101

Light — *Pay careful attention to the light conditions in your photograph:*

• When trying to avoid harsh shadows, shoot photographs of people in covered shade so the light is more even across your subject(s).

• Try to place the sun at your back when you are shooting your photographs. This will help you avoid backlit subjects with shadowy faces.

Shooting — *When shooting a photograph, hold the camera steady and release the shutter carefully*

• Hold the camera with both hands, with elbows against your body and feet spread apart. This helps to avoid camera shake or vibration which leads to unsharp pictures.

Subject — *Have a strong center of interest in your photograph*

• Get as close as you can with your camera to include only what is needed in the frame. Photographs often have extra things in the frame that distract from the center of care.

Framing — *Pay attention to the background in your photo*

• Watch for clutter or for an object like a telephone pole that might appear to be growing out of the subject's head on the final picture.

• Are there elements in your photograph's background that are important for telling the story you want to tell?

Composition — *Composition is the placement of elements (people, objects, environment) in a photograph within the restriction of the frame of the photograph*

• Pay attention to how you arrange the people, objects, and environment in your photograph

Tips:

• Experiment with different lighting. Remember that the flash will not reach very far at night. Be sure to limit night shots to objects that are within arm's length. You may need to use the flash even on a sunny day outdoors.

• Keep the sun behind the photographer when outdoors.

• Keep your finger away from the lens and flash

Photo Game

Challenge #1 - Angles:

Take the same picture from 3 different angles. Try to use horizontal and portrait framing. Play around with looking down on the subject vs. looking up. Use your body and imagination…try crouching or stand on chairs!

Challenge #2 – Staged vs. Candid Photos:

Experiment in the difference between posed vs. unposed photos. Take a picture of someone posing. Now take an image of someone who doesn't know you are photographing them.

Challenge #3 – More than a Face

Experiment with different ways of taking images of people. Take a headshot (a picture of someone's head). Now try taking a picture of them without their face being visible…different body part, with the lighting behind them so their face is in shadow or with an object in front of their face. These tricks can help maintain people's anonymity for personal reasons and safety.

Challenge #4 – Can I take your picture?

Ask someone permission before you take someone's picture! If they say no, explain briefly what you are doing and why you want to take their picture. Your explanation can simply be: "I'm working on a photography project for women and housing issues in the DMV, would you mind being in one of the photos?"

Challenge #5 – What's that?

Take an image where it is hard to tell what the object in the photograph is. Go in close, use different angles and your imagination. Think about the color, texture, etc. See if someone can guess what it is.

Challenge #6 – When you get home

- Feelings – think of different emotions (happy, sad, angry, excited, etc.) Take pictures that convey or symbolize one, two, three or all these different feelings
- Absence – Capture a picture of "something missing". Sometimes it's just as important to take a photo that shows the absence of something as it is to capture the actual person/object
- Themes – Think about your housing situation and shoot a picture of
    - Something you like and something you don't like
    - Your favorite place/thing/person
    - Your community or environment
    - A day in the life of….
    - Your dreams, memories, desires, fears

APPENDIX H: Photo Release Forms

More Than a Shelter:
Photo Consent Form 1

I am part of a Photovoice project investigating what it is like to receive housing support and services. We are taking photographs of our lives and talking about them with other people in our group.

Please sign this form if you agree to let me take your photograph for this project.
If you would like a copy of this photo, please write down your address.

I agree to have my photo taken for this Photovoice project:

_____
Name

_____
Signature

_____
Date

_____
Name of photographer

More Than a Shelter:
Photo Consent Form 2

I give — or refuse — permission for my photos and captions to be used in a public display.

☐ Yes, I am willing to have my photographs and captions used in public displays about housing in Washington, DC.

☐ No, I do not want my photographs and captions used in public displays about housing in Washington, DC.

I also need to give — or refuse — permission for my name to be listed as the photographer.

☐ I want my FULL NAME listed as the photographer

☐ I want only my FIRST NAME listed as the photographer

☐ I want an ALIAS of my choosing listed as the photographer

☐ I DO NOT want my name listed at all.

Please list any concerns or comments:

_____

_____

_____

_____

_____

_____
Name

_____
Signature

_____
Date

APPENDIX I: Contact Information Form

More than a Shelter: Information Form

We need to collect this information about you in order to tell you about the study and meetings.

Name:_____

Address:_____

_____

_____

Phone: (___ ___ ___) ___ ___ ___ - ___ ___ ___ ___

If this is not your phone number, let us know whose it is:_____

Email:
_____

We also want to know:

1. How old are you? ___ ___
2. What is your race or ethnicity? _____
3. How long have you been living with HIV/AIDS? _____

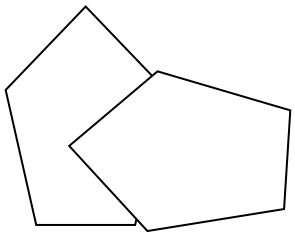
APPENDIX J: Cognitive Impairment Tool

FOLSTEIN MINI MENTAL EXAM

Administer the Folstein Mini-Mental Exam and score each item based on the number of correct answers. Stop when client reaches 21 points. If the participant does not attain 21 points, exclude them from this study.

Administered by: _____ Date:_____

~~Fill~~ → in	Patient's level of education: Limitations: (i.e., sight, hearing, mood, cooperation)
Max Pt Score	**30**
5 _____ 5 _____	<u>Orientation</u>: What is the year? _____ Season? _____ Month? _____ Date: _____ Day? _____ What city are we in? _____ County? _____ State? _____Hospital? _____Floor?_____
3 _____	<u>Registration</u>: Name 3 unrelated objects and have the patient repeat them. (One point for each object named correctly on the 1st repetition.) Although 1st repetition determines score, patient has up to 6 trials. Record # of trials: _____
5	<u>Attention & Calculation</u>: Subtract 7 from 100 and keep subtracting each number (93,

_____	86, 79, 72, 65). One point for each correct answer. (Alternative: Spell W-O-R-L-D backwards. One point for each letter in correct order.)
3 _____	<u>Memory</u>: What are the 3 objects you were asked to remember? (One point each.)
2 _____ 1 _____ 3 _____ 1 _____ 1 _____ 1 _____	<u>Language and Visuo-spatial Skills</u>: Name these objects: (point to watch, then a pencil, one point each) Repeat the following statement: "No ifs, ands or buts". (Allow only one trial.) Follow this command: Take this paper in your right hand, fold it in half and put it on the floor. (One point for each stage performed correctly.) Read and obey this: CLOSE YOUR EYES (One point if he/she closes eyes.) Write a sentence below. (Needs to contain subject and verb. Correct grammar/punctuation not necessary.) Copy this design: 

Total Score: _____

APPENDIX K: IRB Approval Letter

Drexel UNIVERSITY
Office of Research

APPROVAL OF PROTOCOL

January 22, 2016

Augusta Villanueva, Ph.D.
School of Public Health
Drexel University
Mailstop: 660

Dear Dr. Villanueva:

On January 22, 2016, the IRB reviewed the following protocol:

Type of Review:	Initial
Title:	More Than a Shelter: Exploring the Impact of HOPWA Funded Housing in the Lives of Women with HIV/AIDS
Investigator:	Augusta Villanueva, Ph.D.
IRB ID:	1511004020
Funding:	Internal
Grant Title:	None
Grant ID:	None
IND, IDE or HDE:	None
Documents Reviewed:	HRP 211 Application Form, HRP 201 Contact Forms, Conflict of Interest Forms, HRP-503 Template Protocol, HRP-502 consent, Data Collection Tools, Recruitment Flyer, Photo Release Form, Photo Consent Form, Contact Information Form, and Proposal

According to 45 CFR 46, 110, this study is Approved Expedited Categories 6 and 7. This study will enroll 12 subjects recruited from local community based organizations focused on HIV and women's health in Washington, DC to complete surveys and participate in a group discussion session.

The IRB approved the protocol from January 22, 2016 to January 21, 2017 inclusive.

Before December 7, 2016 which is 45 days prior to study closure, you are to submit a completed "FORM: Continuing Review Progress Report (HRP-212)" and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of January 21, 2017 approval of this protocol expires on that date.

Attached is a stamped approved consent document. Use copies of this document to document consent.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

Teresa C Hinton

Digitally signed by Teresa C Hinton
DN: cn=Teresa C Hinton, o=Drexel University, ou=Office of Research, email=tch47@drexel.edu, c=US
Date: 2016.01.28 11:27:10 -05'00'

Teresa C Hinton
Member, Social and Behavioral IRB #3

APPENDIX L: Consent Form

Drexel University
Consent to Take Part in a Research Study

1. ***Title of research study:*** More Than a Shelter: Exploring the Impact of HOPWA Funded Housing in the Lives of Women with HIV/AIDS

2. Researcher: Dr. Augusta M. Villanueva, Principal Investigator; Jenné Massie, co-investigator

3. Why you are being invited to take part in a research study

We invite you to take part because:

- You are a woman age 18 or older.
- You currently receive HIV/AIDS housing services in Washington, DC.

4. What you should know about a research study

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part now and change your mind later.
- If you decide to not be a part of this research no one will hold it against you.
- Feel free to ask all the questions you want before you decide.

5. Who can you talk to about this research study?

If you have questions, concerns, or complaints, talk to the research team at Drexel University. The team can be reached by contacting Jenné Massie at 202-994-0603 or at jsm58@drexel.edu.

This research has been reviewed and approved by an Institutional Review Board (IRB). An IRB reviews research projects so that steps are taken to protect the rights and welfare of participants. You may talk to them at (215) 762-3944 or email HRPP@drexel.edu for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.

6. Why is this research being done?

This study will use photovoice photography and discussion of the photos. Women receiving HIV/AIDS housing services in the DC area will take photos of their lives and discuss their photos.. The outcome of the study is to understand how HIV/AIDS housing programs impact women's lives and potentially their health.

7. How long will the research last?

We expect that you will be in this research study for 1 month.

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Human Research Protection
Protocol # 1511004020
Approval Date: 1/22/16
Expiration Date: 1/21/17

8. How many people will be studied?

We expect about 12 people.

9. What happens if I say yes, I want to be in this research?

You will be asked to participate in study activities for 1 month. You will attend a 1.5 hour training where you will be given your camera. We will ask you to take photos of your experience for 2 -3 weeks. You will meet with Jenné Massie to discuss your photos. Then we will ask you to attend a group photo discussion session with other participants.

You will be asked to complete a brief demographic survey during training.

All individual and group sessions will be audio recorded and transcribed by the project coordinator.

We will also ask you to provide contact information. We will use this to contact you about any future presentations or use of the photos.

10. What are my responsibilities if I take part in this research?

If you take part in this research, it is very important that you:

- Follow the research team's instructions.
- Tell the research team right away if you have a complication or injury.
- Obtain photo release waivers from anyone that you photograph that can be easily identified
- Submit photo release waivers for any pictures that the researchers may use in future presentations and publications

11. What happens if I do not want to be in this research?

You may decide not to take part in the research and it will not be held against you.

12. What happens if I say yes, but I change my mind later?

If you agree to take part in the research now, you can stop at any time it will not be held against you.

If you decide to leave the research, you will be asked to return your camera. You will only be compensated for the individual and group sessions that you attended. If you decide to leave the research, contact the Jenné Massie at 202-994-0603 or jsm58@drexel.edu.

If you stop being in the research, already collected photographs and audio may not be removed from the study database.

13. Is there any way being in this study could be bad for me?

Physical Risk: We do not expect you will experience any physical risks during the study

Psychological/Emotional Risks: Discussing photographs with researchers and other participants may make you uncomfortable, emotional or upset.

Privacy Risks: Privacy risks are minimal You will be allowed to decide what photos to share, and choose an alias for yourself or anyone photographed. Only photos accompanied by a photo-release will be used in future research presentations and publications.

Legal Risks/Mandatory Reporting: We are mandated to report to authorities in particular instances of illicit activity such as child abuse, life threatening to self or others, and elder abuse.

APPROVED
Human Research Protection
Protocol # 1511004020
Approval Date: 1/22/16
Expiration Date: 1/21/17

APPENDIX M: Interpretive Phenomenology Interpretations Diagram